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examining the experience of former young carers of people with severe mental illness

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Coping with mental illness: examining the experience of former young carers of people with severe mental illness

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Thesis submitted in fulfilment of the requirements of the degree of Master of Philosophy

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LIST OF ACRONYMS

BBC	British Broadcasting Corporation
CAG	Clinical Academic Group
CASP	Critical Appraisal Skills Programme
CBCL	Child Behaviour Check List
CDRS-R	Children's Depression Rating Scale - Revised
CES-D	Centre for Epidemiological Studies Depression scale
CMHT	Community mental health team
CoPMI	Children of Parents with Mental Illness
CPN	Community psychiatric nurse
EPOC	Cochrane Effective Practice and Organisation of Care Group
EYCP	Edinburgh Young Carer Project
FRS	Family Resources Survey
GP	General Practitioner
ICD-10	International Classification of Diseases - 10
IoPPN	Institute of Psychiatry, Psychology and Neuroscience
IPA	Interpretative Phenomenological Analysis
KCL	King's College London
MRC	Medical Research Council
NHS	National Health Service
NRES	National Research Ethics Service
NRS	Non-randomised studies
ns	non significant
PANOC-YC20	Positive and Negative Outcomes of Caring
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
R&D	Research and Development
RCT	Randomised Controlled Trial

REC	Research Ethics Committee
SCIE	Social Care Institute for Excellence
SIGLE	System for Information on Grey Literature in Europe
SLaM	South London and Maudsley NHS Foundation Trust
SMI	Severe mental illness
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
TAU	Treatment as usual
UK	United Kingdom
YCOPI	Young Caregiver of Parents Inventory
YSR	Youth Self Report

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“All that I am, and ever hope to be, I owe it all to Thee. To God be the glory for the things He has done.”

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PROLOGUE

I am blessed to have the best family in the world and I cannot be grateful enough for them. Yet, growing up, I could not understand why an adult family member had strange moods. Why would somebody get angry or upset over trivial things? It was confusing - we all loved each other, and yet there could be so much distress at times. I began to understand a little during my undergraduate degree in Psychology, but it was only when a post as a carer researcher came up that I found out that a family member was formally diagnosed with severe depression. It explained some things. I applied and was accepted for the post and was enabled, through it, to begin a higher degree. This research journey has also been a personal one. I have learnt a lot about mental illness, about families with mental illness. I am deeply privileged to have met young people who faced such daunting situations and dealt with them with love and courage. By sharing their stories with me, they helped me gain insight and understanding, although I cannot compare my story with theirs. This journey has been incredibly fulfilling; I have learnt a lot about research, about mental illness, about families, and I am deeply grateful to God for guiding me through it. It is my hope, and I believe my participants' hope, that this will be useful for other young people who have helped to look after someone with a mental illness.

ABSTRACT

Introduction: Research has explored the factors that contribute to caregiving and subsequent support needs, and the stress process model has been used as a theoretical framework for adult carers of people with a severe mental illness (SMI). However its applicability to a population of young carers looking after someone with SMI is yet to be explored. The aim of this study was to identify a theoretically informed model for young carers of those with SMI as a guide for the future development of more supportive interventions for this group of carers.

Method: The thesis was based on a constructivist approach, which took into account multiple perspectives, including the researcher's own lived experience. A focus group discussion with 10 participants and in-depth interviews with 14 participants were conducted, from a sample of 23 young people with experience of caregiving for a relative with SMI. The data collected on young carers was retrospective, since the participants were all former young carers, and some were also young adult carers. Additionally, the interventions suggested were fed back to a nominal group with 4 of the interviewed participants, and individual interviews with 7 young carer support workers were conducted. The thesis was structured on the Medical Research Council (MRC) guidelines for developing complex interventions which suggests the following elements as part of the development phase: (i) identifying the evidence base; this was done via systematic review, (ii) developing theory; qualitative methodology was used, (iii) modeling process and outcomes; the data informed a stress process model for young carers.

Results: (i) Identifying the evidence base*:* A systematic review of interventions for children, siblings and young carers of people with SMI was conducted to identify the evidence base for effectively supporting this population. 14 studies were identified as relevant and a narrative review undertaken to incorporate differently designed studies. There were few high quality studies focused on those whose parents have affective disorders, and no studies found of family members with psychosis. *(ii) Developing theory*: Data from the qualitative study were analysed using thematic analysis. The contextual factors and stressors which are present need to be considered for the outcomes of a young person providing care. A range of emotional, information and

instrumental support needs of a young person caring for somebody with a severe mental illness were found to be important. *(iii) Modelling process and outcomes*: Using the stress process model as an example, an adapted model for young carers of those with SMI was proposed.

Discussion: As evidenced previously, young carers of those with SMI have somewhat different needs from adult caregivers. Young caregivers also need different amounts of support at different stages, particularly age appropriate information. It is suggested that any intervention would need to consider the likelihood that some young people without caregiving responsibilities and who do not live with the person with SMI might also need support, corroborating the need for a whole family approach. The thesis provided a relevant theoretical framework within which to plan interventions for this population, and provides tentative support for the hypothesis that increasing coping and social support will mediate better outcomes. The results from the qualitative study are discussed in comparison with the literature for adult caregivers of people with SMI and other young caregivers, as it was found that current support did not ensure better outcomes. The limitations and strengths of the study are discussed and the thesis concludes with implications for practice and policy. While it adds to the evidence and argument for a whole family approach to supporting young carers, it also has importance for the development of interventions for this population, such as specific information, recognition of the role and its impact, both by services and in educational settings, and the need for a range of support particularly other family/confidante support. There is an urgent need for these kinds of support for this neglected group of carers.

CHAPTER 1: INTRODUCTION

This chapter aims to provide an understanding of the term 'young carer' and the current policy and services for this population in the United Kingdom. It also lays out the theoretical underpinnings for the thesis, describing the health services research and sociological perspectives before progressing to the stress process model. The chapter considers current literature in both adult carers and then young carers of people with SMI in the context of the stress process model suggested by Pearlin et al (1990). Identifying the gaps in theory and knowledge lead to the study aim and objectives.

Who are young carers?

Defining a 'young carer'

There are several definitions of young carers. In the Blackwell Encyclopaedia of Social Work, Becker defines young carers as "children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult" (Becker, 2000, p.378). Taking an example from young carer services, the Edinburgh Young Carer Project (EYCP) used the following definition "A young carer is a young person aged 5–25 whose life is affected by the illness or disability of someone in his or her family. They may provide physical and/or emotional support for that person" (Cree, 2003, p. 301).

It has been argued that definitions based on caregiving responsibilities risk excluding children who might benefit from support (Newman, 2002). Becker's definition emphasizes the level of caring responsibility, while Newman (2002) posits that although definitions based on the restrictions placed on young carers and on impact might be more inclusive, this might inflate the concerns about young carers without sufficient supporting evidence. However, in this thesis, using a more inclusive definition allows the differences between caregivers and non-caregivers to be better understood.

The prevalence of young carers of people with mental illnesses in the UK

The Family Resources Survey (FRS) collects information from private households in the United Kingdom on those giving and receiving care informally and estimates that in 2010/11 there were 100,000 children who were carers, a figure that has remained broadly stable over most of the last decade (Department of Work and Pensions, 2012). However, in a survey of schoolchildren by the British Broadcasting Corporation (Howard, 2010), 8% of the participants responded that they carried out 'personal care' of someone at home (i.e. helping the person to dress or undress, to have a wash, or to have a bath or shower) either 'a lot of the time' or 'some of the time' in the previous month. Taking that to be a proxy indicator of caring activity and extrapolating from those figures, the number of young carers was estimated to be about 700,000, which was four times as many as previously thought (i.e. 175,000)[1]. Even these recent figures differ widely and it is difficult to estimate the accuracy of the surveys: for the FRS, information on children in the household is collected by proxy from an adult, so it may be presumed that it was through adults that the estimate of young carers was gathered, and adults might not be willing to admit that their children are providing care. On the other hand, the BBC article provides little information about its survey methods, for example, how the schools were selected to be surveyed and how children were sampled within each school, so it is unclear how representative of the UK population their sample is. The wording of the questionnaire also means that the respondents may not necessarily be caring for somebody who is ill. Their estimates also contrast strongly with the 2011 Census which identified 177,918 young unpaid carers (5 to 17-years-old) in England and Wales (an increase of almost 19% since 2001), of whom 54% were girls (ONS, 2013). In England and Wales, 142,768 (80.2%) children and young people provided up to 19 hours of care, 19,422 (10.9%) provided 20 to 49 hours and 15,728 (8.8%) provided 50 or more hours of unpaid care per week.

The estimates of young carers looking after someone with a mental illness are more uniform. Aldridge and Becker (2003) draw together the results from three surveys of young carer projects, which suggest that 29% of children in contact with young carer projects in Britain are caring for a family member with mental health problems

[1] Information from the BBC news article was supplemented by personal communication with Prof Saul Becker of the University of Nottingham

(including alcohol and substance misuse), and the figure from London projects was only slightly higher (30%). This is consistent with Dearden and Becker's third survey of young carer projects in 2003 which found that 29% of the people with care needs had mental health problems (Dearden and Becker, 2004). The BBC survey also estimated that 29% of the schoolchildren who took part were providing 'emotional care' for a family member 'some of the time' or 'a lot of the time', which was considered to be indicative of caring for someone with a mental illness, including alcohol and substance misuse (Howard, 2010). However, surveys of those in contact with young carer projects are unlikely to be representative of the general population, and emotional care is not necessarily an indicator of mental illness alone, since young people could be providing emotional support for people with other conditions.

The role of young carers looking after somebody with a mental illness

In addition to tasks carried out by children whose parents have physical health problems, children whose parents have mental health problems frequently provide "critical crisis support" (Aldridge, 2006, p.81) when their parents' mental health worsens. They also monitor their parents' mental health and well-being and sometimes have to supervise their medication. However, the findings of their study with young carers, parents and professionals suggest that the care provided by young carers is not a reversal of the parent-child roles. While children might adapt their roles to meet the situation, both they and their parents feel that the parental status remains (Aldridge, 2006). On the other hand, young people caring for a parent with a mental illness can also have additional responsibilities, e.g. looking after other family members or mediating family conflicts (Grant et al., 2008), which suggests otherwise.

The rights of children

Aldridge (2008) suggests that the difference between young carers and children of parents who are not ill or disabled is the lack of choice in taking on caregiving responsibilities. She also describes the contradiction of caregiving, wherein children are seen to be entitled to a childhood, envisioned as lack of responsibility, and at the same time expected to take on adult responsibilities. The UK Government identified the key outcomes for every child as: being healthy, staying safe, enjoying and achieving, making a positive contribution, and economic well-being (DfES, 2003). Children's

rights, and thus their outcomes, can be undermined, depending on the context, in terms of the child's safety, or physical health and wellbeing, or financial stability and well-being through loss of income due to chronic illness or disability, or enjoyment and achievement (Aldridge, 2008). A study of the perspectives of health practitioners with regard to young carers of parents with mental health problems further highlighted the associative stigma, social and peer group isolation, and the restrictions in education, leisure time, prospects and employment as some of the challenges faced by young carers (Gray et al., 2010).

A children's rights approach involves recognition of young carers and their expertise, their agency or right to choose, from their perspective. This convergence of their rights as children and as carers has begun in public policy (Aldridge and Becker, 2002), for example with the Carers' Strategy 2008 (HM Government, 2008, described in more detail below), which identified the need for support for young carers but also their right to continue to choose to care for a family member. Rather than seeing young carers as unpaid, unsung heroes, Aldridge (2008) argues for an approach that focuses on their needs. However, Aldridge (2006, 2008) also challenges the notion that parental mental illness is a risk for child abuse, neglect and developmental delay and suggests that caregiving could strengthen the bonds between parents and children. On the other hand, there is some acknowledgement that the experience of caring might have adverse effects, if it is for a long period or if the child's age and maturity are not sufficient to meet the responsibilities. Newman (2002) also argues that focusing on the potential for negative long-term impact on young carers may actually be more harmful.

Policy and provision of services

When planning for this study began in 2008, the Government had just published its new Carers' Strategy (HM Government, 2008) with its vision for carers by 2018 to be recognised and valued, with support tailored to the individual's needs, enabling carers to have a life of their own, to stay healthy and not to be forced into financial difficulties by caregiving. It envisioned that young carers would be protected from excessive or inappropriate (i.e. for their age) caring and committed to increasing the support from services, particularly those focusing on families. The Strategy recognised that there could be positive aspects to caregiving and that young carers did not want to stop caring altogether, but that caregiving could have a negative effect and constrain a child from

reaching his/her full potential. Thus, the focus was on preventing young people from falling into inappropriate caring; this could be achieved by creating awareness in schools and extending the existing support to include young carers, training teachers and health professionals to identify and support young carers, providing targeted services and improving whole family services. This Strategy was more detailed in its commitments to support young carers than the first Carers' Strategy (Department of Health, 1999), which included a section for young carers, and highlighted the issues of sole carers, young carers from ethnic minority groups and children in families where a parent has a mental illness. It described some of the negative effects of caregiving, young carers' needs and plans to improve recognition of and support for young carers by local authorities and health, education and social services. Of particular note is the reference to the Carers (Recognition and Services) Act 1995, emphasizing that young carers are also eligible for an assessment of their own needs.

The Act enabled a carer to request the local authority to assess their ability to provide care for a person, before the authority decided that the person required the provision of services. However, the provision was for a carer who "provides or intends to provide a substantial amount of care on a regular basis for the relevant person" (HM Government, 1995, p. 2)[2]. In 2004 it became the duty of the local authority to inform the carer that they might be eligible for an assessment (Carers (Equal Opportunities) Act 2004). The assessment needs to consider whether the carer is working or wishes to work, or is undertaking or wishes to undertake education, training or any kind of leisure activity. Furthermore, the 2004 Act required the cooperation of different authorities (e.g. education, housing) in the provision of services for either the carer or the person receiving care.

The guidelines put forward jointly by the Children's Society and the Princess Royal Trust for Carers (Frank, 2002) include key messages regarding families where there is a parent with mental ill health. Agencies are urged to consider the needs of parents and children jointly and to offer a flexible range of services. Practitioners are encouraged to promote the parents' capacity to parent and the children's welfare. However, working

[2] According to the supplementary Policy Guidance and Practice Guide issued in the same year by the Dept. of Health (as cited by Aldridge & Becker, 2003), it is for the local authority to decide what constitutes 'regular' or 'substantial' care; those carers who do not provide regular or substantial care are still eligible to have their opinions taken into consideration during an assessment. Care includes emotional support.

together to address the needs of a family continues to be difficult; a recent report indicated that young carers are no more likely than their peers to come into contact with support agencies (The Children's Society, 2013).

There are a large number of groups and projects for young carers, including some specifically for young carers of people with mental health problems and these are valued by both the young carers and their parents (Aldridge, 2006). Young carers groups and forums are viewed by professionals as a means of supporting young carers by providing a safe place for them to meet other people, combating stigma and isolation, and by facilitating informal information-sharing (Gray et al., 2008). Despite the increase in support for young carers, the estimate in 2007 of more than 350 young carers' projects in contact with around 25,000 young carers, contrasts sharply with the prevalence estimates seen earlier. This suggests that a large number of young carers do not access services (Becker, 2007). The 2004 report of young carers in the UK found that only 18% of young carers surveyed (and this was only those in contact with young carer projects) had been assessed, mostly under the older Children Act of 1989, although this was an improvement from their earlier survey (Dearden and Becker, 2004).

The particular case of young adult carers

Young adult carers are defined as "people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse), connected with a need for care, support or supervision" (Becker and Becker, 2008, p.6). The same authors estimated that 5.3% of all young people aged 18-24 in the UK are carers. Specific to this group are the difficulties of increasing demands alongside their caregiving responsibilities, balancing caregiving with their education either by 'caring at a distance' or travelling to University, insufficient time for themselves and its impact on seeking employment, financial difficulties, and the impact of caregiving in mediating their future aspirations. In particular, there is a gap in provision of services for this age group, since they neither belong to the young carers services, nor do they usually find it possible to fit into services for working age adults.

Becker & Becker (2008) also distinguish between young carers aged 16-17 and those who are younger, since the former group are at different stages of development and of caregiving from the latter. This can be seen in the constraints that prevent them from going out more or from leaving home, the importance of educational and career support, and the lack of information and subsequent concern about services available after they turn 18. While the Becker study has identified that some young adult carers did not receive a young carers service, the limitation is that most of their sample were recruited through young carers services, making it difficult to consider the experience of those who never receive support.

The Carers Trust in a press release (http://www.carers.org/press-release/carers-trust-calls-government-seize-opportunity-support-young-carers-after-83-increase) suggested that the 2011 Census showed a 25% increase from the previous census in the number of 16-25 year olds providing care, but these numbers could not be verified. Although there is limited research on this population, young adult carers are less likely to be in employment, education or training than their peers (Audit Commission, 2010) and, with cuts in services, are less likely to access information advice and guidance available from the Local Authority (NIACE, 2013). Cass et al (2009) in Australia found that more of their young adult carers took on primary caregiving responsibilities than the young carer group in general. Consistent with the Becker & Becker research, young adult carers in their study indicated restrictions in education and employment, as well as feeling 'different' from their peers.

Examining theoretical models

The theoretical underpinnings of research on this population in general range include risk and resilience models, disability rights approaches, and stress/coping models.

Risk and resilience in children of parents with mental illnesses

Studies of the impact of parental mental illness tend to focus on the risk of mental health problems in the children (e.g. Birmaher et al., 2009, Cowling, 2004, Manning and Gregoire, 2006). The Crossing Bridges Family Model was recommended by the Social Care Institute for Excellence (SCIE) for staff in mental health and children's services as a model for working with the whole family when providing care for a parent with a mental health problem. The model is based on three relationships: the risk of

impact of parental mental illness on a child's mental health and development, its potential consequent impact on the child's mental health as an adult, and the effect of the child's emotional/behavioural/other difficulties on the parent's mental ill health. The model also suggests that there are risk factors (both personal, e.g. domestic violence, and environmental, e.g. lack of community support) which act cumulatively to worsen the outcome, as well as protective factors (e.g. physical and personality traits) that can enhance resilience and enable the family to overcome its difficulties (SCIE, 2009, citing Falkov, 1998).

Bee and colleagues at the University of Manchester (2014) considered parental SMI as a challenge to the quality of life of their children. They used a qualitative approach to identify three key elements to the resilience of CoPMI: alleviation of parental mental health symptoms, improved problem-based coping skills and increased mental health literacy. According to Parrott, Jacobs & Roberts (2008), key to building resilience is a sense of security, recognition of self-worth and a feeling of control, as well as understanding the importance of resilience itself. Parental bonding, social support, optimism and perceived control are other significant contributors to resilience.

A sociological perspective

Authors in the young carer literature argue for a children's rights approach that involves recognition of young carers and their expertise as well as their agency or right to choose (Aldridge, 2008). Since caregiving by children and young people is likely to be an "inevitable social reality" (p.13) and that having a parent with an illness/disability is likely to lead to some caregiving by their children, it is argued that the rights of both children and parents must be considered, without prioritising one over the other (Aldridge and Becker, 1999). The argument is that caregiving by children would not be necessary if adequate support were in place, but also that young carers can, and often do, choose to care. However it is a somewhat narrow view of the problems, because it does not consider other factors, e.g. the severity of the mental illness, that might contribute to the difficulties faced by the young carer.

Social and economic factors undoubtedly have a role in the impact of illness on children and families. The Young Carers Research Group at Loughborough University has emphasised the importance of factors such as single parenting, low income, inadequate

support from services and social networks on negative outcomes in caregiving (Aldridge, 2008) in addition to the onset of parental mental illness. Aldridge (2002) identified a lack of sufficient support from services as one of the main reasons for children to have to provide care. Becker (2007) similarly identified a lack of other informal care, of available and affordable health and social care services, and a lack of support for the parenting needs of ill or disabled people for young carers in general. Thus, identifying additional or secondary stressors which may exacerbate negative outcomes, is important both for understanding what can support young carers and what can improve their outcomes.

Rationale for choosing a theoretical approach

A risk-resilience model is useful in that it highlights the importance of identifying and supporting young carers at risk of negative impact, but also takes into consideration that not all children are negatively affected, that there can be positive effects, and factors that nurture resilience. Professionals may assume risk of negative impact for children living with or caring for parents with mental illness that is unjustified. This model also does not take the perspectives of the parents or the children into consideration, for example, that children as individual agents have a right to choose (Aldridge, 2008). The disability rights perspective on young carers moves beyond a focus on the negative impact of parental ill health, arguing instead for the need for adequate and comprehensive support services. Furthermore, while parental ill health will be a factor in determining caregiving, a disability rights perspective for young carers focuses on the rights of young people as children and as carers, but not to the exclusion of their parents' rights (Aldridge and Becker, 1999).

Research is moving away from the notion of 'dysfunctional' families (i.e. families not operating properly because of societal difficulties), and instead focusing on adaptation and adjustment (Saunders, 2003). The concept of caregiver appraisal emerged in the 1990's to supplant the focus on burden, and continues to be helpful (Kate et al., 2013, Szmukler et al., 1996). Understanding the way in which families respond to illness and how they cope with it is important in order to understand how to support them. "Stress, appraisal and coping are strongly intertwined; illness is an important source of stress and coping with this stress is influenced by just how it is appraised" (van der Voort et al., 2007, p.683).

The stress process model has been used as an explanatory model for adult caregiving in severe mental illness. While a sociological model argues for a whole family approach to supporting young carers, it is helpful to have a basic model that will indicate theoretical routes or mechanisms for intervention. This does not preclude a whole family approach or a rights perspective, despite an apparent focus on negative outcomes. It also includes a wide range of factors in the experience of caregiving. Finally, emerging themes suggested this model as a potentially good fit.

Definitions of severe mental illness

While the literature has included different kinds of mental health problems in those cared for by young carers, it has rarely addressed the severity of the illness. Research into young carers of those with psychotic disorders is particularly lacking. In order to study this population, the definition of severe mental illness (SMI) first needs to be examined. These definitions have tended to focus not only on the type of illness, but also the functional impact, duration and risk (e.g. Barker and Gregoire, 2000, Ruggeri et al., 2000, Schinnar et al., 1990). While studies of SMI tend to focus on psychotic disorders, it has been shown that non-psychotic illnesses can also be severe in duration of treatment and severe dysfunction (Ruggeri et al., 2000), and carers may also need services. Thus a definition of SMI that considered not just the type of illness, but also the impact, such as the one below, was needed for the study.

A. Either symptomatic psychotic illnesses, or symptomatic bipolar affective disorder, or receiving antipsychotic or mood-stabilising medication for either diagnosis (OR)

B. Unipolar depression; neurotic, stress-related and somatoform disorders; behavioural syndromes; organic disorders

AND either functional impact or significant risk of suicide or harm to others (Barker and Gregoire, 2000).

The stress process model

Pearlin and colleagues (1990) developed the stress process model to describe the factors affecting the course and outcome of caregiving through their research on caregivers of people with Alzheimer's disease. They described this as a process, stating "the very notion of process forces attention on the relationships among the many conditions

leading to personal stress and the ways these relationships develop and change over time" (Pearlin et al., 1990, p.585). The conceptual components of the stress process model, as described in the same article, include:

1. Background and contextual factors: These are factors within the personal context that are likely to affect the kinds of stressors to which caregivers are exposed, the resources available to deal with the same and the subsequent outcomes. They include the socio-economic characteristics of the caregivers (e.g. age, ethnicity), the caregiving history (e.g. relationship with the patient, duration of the illness), the size and nature of social networks, and the availability of community support services.

2. Primary and secondary stressors: Stressors are the problems faced by caregivers. Primary stressors are those problems that directly stem from the patient's needs and the amount of care that those needs demand. The cognitive status of the patient is a primary stressor specific to Alzheimer's disease, something that the caregivers are able to assess for themselves with reasonable accuracy. Other primary stressors include the problematic behaviour of the patient and the level of vigilance required of the caregiver, and the level of dependency on the caregiver. However, the latter is more stressful in relation to the amount of resistance offered by the patient. Finally, there are also two primary stressors that are more subjective in nature: relational deprivation, i.e. the loss of the reciprocal relationship with the patient, and the feeling of overload or burnout.

   Secondary stressors are derived from primary stressors and comprise two kinds - role strains, from roles and activities outside the caregiving situation, and intrapsychic strains, from dimensions of self-concept and similar psychological states. The former includes conflicts within the family, occupation problems, economic strains and restrictions on social activities. The latter indicates that self concepts such as mastery and self-esteem could be damaged in times of strain; there are also situation specific concepts such as role captivity, loss of self, competence and personal gain.

3. Mediating conditions, such as social support and coping mechanisms explain how similar stressors affect people differently. Pearlin and colleagues suggest that mediating conditions can act both by buffering the direct effect of the stressors as well as muting the development or proliferation of secondary stressors. Coping can

be management of the situation, of the meaning of the situation, or of the stress symptoms as a result of the same. Support is derived from a portion of one's network and Pearlin's model focuses on instrumental and expressive types of support.

4. Outcomes: The outcomes considered as a result of stressful caregiving experiences include the caregiver's wellbeing, mental and physical health, and their ability to continue in their role.

A copy of the model by Pearlin et al (1990) can be seen below in figure 1.1.

Fig 1.1. A conceptual model of Alzheimer's caregivers' stress (from Pearlin et al., 1990, p.586)

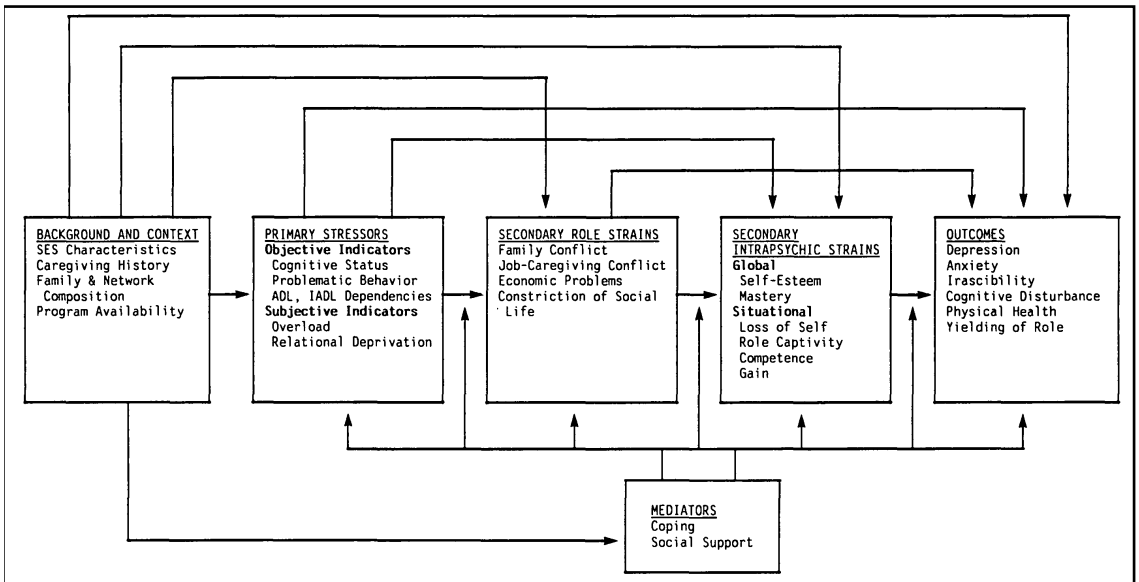


Figure 1. A conceptual model of Alzheimer's caregivers' stress. The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.

The stress process model in severe mental illness

The stress process model is also applicable in severe mental illness, as shown in the following studies. The way in which caregivers evaluate the caregiving situation and the adequacy of their coping resources is related to their beliefs about the illness and these help to determine their level of subjective burden. Particularly, the caregiver's perception of the degree to which the patient has control over the illness and is attempting to do so affects the level of subjective burden experienced by the carer (van der Voort et al., 2007). Perlick and colleagues (2008) found that caregivers of patients with bipolar disorder who reported higher subjective burden also had higher levels of avoidance coping and lower levels of mastery and social support. Burdened caregivers

also showed greater negative outcomes such as depressive symptoms, sleep problems and service use. Caregiver stress stemmed from illness symptoms and associated behaviours rather than external factors like stigma and discrimination. However, those facing stress from stigma had slightly more negative outcomes than those who employed more effective coping strategies through less adequate self-care and perceived lower levels of mastery. This study indicates some of the variables within the stress process model for adult caregivers and identifies the importance of age as a variable in caregiving in relation to older carers.

Stress as a model has been adapted to conceptualise caregiving for psychiatric illnesses (Zegwaard et al., 2011), and the stress process model has also been applied in studies of other mental illnesses. For example, Coomber et al (2013) identified that carers of people with eating disorders show evidence of a long-term impact in terms of burden and psychological distress. They further identified that coping strategies change over time, becoming more maladaptive, while satisfaction with social support remained stable. Poor relationships, maladaptive coping and unmet carer needs were significant predictors in the long term for carer burden. More importantly, social support was not found to be a predictor of burden, and psychological distress could not be predicted longitudinally, potentially indicating its situational nature. The lack of evidence for social support as a predictive factor could have been due to the use of a general measure of emotional support, given that social support is an intrinsic factor in the stress process model, and there is evidence of the impact of social support in other studies of eating disorders. Raenker *et al.* (2013) found that high levels of objective burden (time spent caregiving and number of tasks) were related to caregiver psychological distress, but mediated by their subjective burden. The perceived quality of social support partially mediated the relationship between subjective burden and distress.

Thus the stress process model has been shown to be applicable in the context of caregiving for severe mental illness. Elements of the stress process model are explored further below.

Stressors in caregiving for severe mental illness

Early studies have shown the difficulties faced by family members in dealing with difficult behaviour, particularly the negative symptoms of psychosis, the negative

impact on their relationship with the ill person, for instance someone with depression, and on social activities and relationships (Fadden et al., 1987). Zegwaard and colleagues (2011) reviewed the literature to identify the determinants of stress in informal caregivers of older adults with psychiatric disorders. These included problematic behaviour of patients, caregiving tasks and emotional consequences. Changes in mood and behaviour and the severity and frequency of problematic behaviour, particularly negative symptoms and passive behaviour are seen as a stressor. The nature of the illness affects the tasks required for caregiving, and an increase in the number of tasks and in the patient's dependency can occur. The everyday impact of caregiving, the expectations for recovery, the resultant isolation, difficulties with reciprocity in the relationship with the patient and the sense of loss due to the illness are all part of the emotional consequences and act as stressors (Zegwaard et al., 2011).

Similarly, problems identified by carers of people with schizophrenia include the chronic nature of the illness, concerns about the patient's future, communication problems/conflict with the patient and not enough information on relapses and their prevention (Graap et al., 2008). Another review identified behavioural disturbances, functional/physical/cognitive impairments, and fear of attempts at suicide as patient-related risk factors (Shah et al., 2010). The latter review further indicated gender, age, caregiver health, ethnicity and social support as risk factors for psychological distress in carers.

The impact of caring for somebody with severe mental illness

Research on the impact of caregiving has tended to focus upon the subjective and objective burdens reported by carers, consequently viewing carers as a 'site of intervention' (Sadler and McKevitt, 2012). The burden of an illness was its impact on the patient or the family, which was initially assumed to be negative. Objective elements of burden related to the individual, include symptomatic behaviour and duration of illness, while the composition and sociodemographic variables of a family determine objective burden. Subjective burden may be understood through the stress process model and through the coping strategies utilised at both the family and the individual level (Schene, 1990). The consequences of burden include adverse effects on carers' mental health - e.g. anxiety (Cooper et al., 2007), depression (Saunders, 2003) and distress (Hirst, 2005) - quality of life, use of health services and financial situation

(Schulze and Rossler, 2005). The prevalence of psychological distress experienced by family caregivers of people with schizophrenia can be twice as high as the general population (Oldridge and Hughes, 1992), but the study had a very small sample. In a small pilot study conducted by Graap and colleagues (2008), more than 80% of the 30 carers interviewed stated feeling depressed and 'burned out', or feeling physically or mentally ill.

Caregiver burden is associated with the level of patients' disability (Magliano et al., 2000) and the kinds of symptoms exhibited (van der Voort et al., 2007), but it is also associated with the kinds of coping strategies used by family carers, their attitudes to the patient's illness, and the level of support received (Magliano et al., 2000). The experience of the stigma of mental illness, as well as the level to which caregivers find satisfaction in their caregiving role, are other factors associated with the level of burden (van der Voort et al., 2007).

The literature on siblings of people with mental illness is mainly based on the experiences of adult siblings. In a qualitative study, adult siblings of schizophrenia patients described the impact of the illness on their lives in terms of a continuum from pervasive (affecting all areas of their lives) to discrete (less impact, only in particular areas), but also included examples of positive impact .

Table 1.1. Impact of caring for different mental disorders (from Shah, Wadoo and Latoo, 2010, p.20)

Table 1: The impact of caring for different mental disorders and associated risk factors

Mental Disorder	Risk factors	Impact on the carer
Schizophrenia[28]	High disability, very severe symptoms, poor support from professionals, poor support from social networks, less practical social support, violence.	Guilt, loss, helplessness, fear, vulnerability, cumulative feelings of defeat, anxiety, resentment, and anger are commonly reported by caregivers.
Dementia [29,30]	Decline in cognitive and functional status, behavioural disturbances, dependency on assistance[31]	Anger, grief, loneliness and resentment.
Mood disorders	Symptoms, changes in family roles, cyclic nature of bipolar disorder, moderate or severe distress.[32]	Significant distress,[33] marked difficulties in maintaining social and leisure activities, decrease in total family income, considerable strains in marital relationships.[34, 35] Psychological consequences during critical periods also persisting in the intervals between episodes in bipolar disorder,[36] poorer physical health, limited activity, and greater health service utilization than non-caregivers.[37]

The table above from Shah, Wadoo and Latoo (2010) indicates the impact of caregiving

for a range of mental health problems; there are few differences across the different conditions.

Coping and social support in caregiving for SMI

Families cope in different ways with the stress of severe mental illness in a family member. Problem-solving coping mechanisms, including seeking support, have been found to be particularly effective. Poor coping resources and less social support can result in increased burden, but while severe mental illness is seen as a stressor, it can also improve the coping skills in families (Saunders, 2003). Although a European cohort study (Magliano et al., 2000) found carer burden to be mainly stable over time, where there was a reduction in burden it was predicted by lower levels of coping strategies like avoidance and resignation and higher levels of received practical support and social interests. This is consistent with the findings of a review of the dementia caregiver literature that problem-solving and acceptance strategies are advantageous (Kneebone and Martin, 2003). In relatives of people with schizophrenia, higher distress scores were associated with greater use of self-blame and less use of positive reframing and acceptance (Fortune et al., 2005). The same study also found that higher distress was associated with stronger threat (i.e. primary appraisals) as well as the caregiver's perceptions of the illness. The effect of illness perceptions, particularly perceptions of illness control and illness identity (recognizing symptoms associated with diagnosis), on distress is mediated by coping strategies (Fortune et al., 2005). A study of caregiving for schizophrenia in India (Kate et al., 2013) found that caregivers' subjective burden was most strongly related to their psychological distress, mediating their coping strategies, the age of the caregiver and the time spent caregiving. The caregivers' coping strategies in turn were associated with both objective and subjective burden, mediating the relationship between the time spent caregiving each day and subjective burden.

However, the kinds of strategies that are classified as being either approach or avoidance coping and the relationship of coping strategies to caregiving outcomes tends to vary from study to study. Kneebone and Martin (2003) explore the potential for the effectiveness of the coping strategy used being due to the specific caregiving stressor, since particular strategies may be useful for particular problems. A severe mental illness can also go through different phases with different caregiving tasks and therefore different coping strategies (van der Voort et al., 2007, citing Rose et al, 2002).

Schene (1990) posits that a move away from burden of caregiving on families towards a focus on the needs of the families is called for, in order to recognise the positive aspects of family care and the need for available support when a family's coping resources are insufficient.

The need for information about the illness in adult caregivers of people with mental illness and for support from healthcare professionals has been well documented (Fadden et al., 1987). This includes the need for emergency help, for information about the illness and about the treatment (van der Voort et al., 2007). Psychoeducation/ information and emotional support continue to be the most needed interventions, according to carers of those with schizophrenia (Graap et al., 2008).

When adult siblings of persons with schizophrenia, in a study by Friedrich and colleagues in the US (2008), were asked to rank their own current needs, the most prominent was services for the ill sibling. This was followed by the need for open communication in the family, emotional support from loved ones and information about the sibling's illness. Three of the top five ranked requirements of mental health services were related to information: availability to answer questions, education about schizophrenia and avoiding blaming the family. The top ranked coping strategies were also related to information – understanding that schizophrenia is a disease and not anyone's fault, and reading schizophrenia literature - followed by the availability of a supportive family. The representativeness of the sample was an issue, however, since they were not recruited from the general population but from a self-help group and through other referrals, and they were primarily Caucasian and educated to college level.

Cohen (1985) proposed that social support could act as a buffer in times of stress, either at the point of appraisal or at the point of a negative stress response. Furthermore, cumulative stressors such as caregiving are seen as having more negative impact than other stressors. The characteristics of the social network and the kind of support (instrumental, emotional, informational) provided have an impact on the objective burden of a family while the level of perceived support affects subjective burden (Schene, 1990). Magliano and colleagues (2000) found lower levels of subjective and objective burden in relatives of people with schizophrenia who had more extensive and supportive networks. Supportive networks had a positive impact on burden in female

caregivers but this effect was not found in male caregivers. Moreover, relatives with higher support levels reported less pessimism about the patient's opportunity to reach social and affective goals.

Social support is also related to carer coping strategies. Magliano and colleagues (1998) found higher perceived levels of friends' understanding and social support were associated with more problem-focused coping, whereas resignation and avoidance were associated with poor social support. Social support is seen as an important coping resource for families affected by severe mental illness, particularly given its isolating nature, with support sought from family members, friends and those with similar experiences. Social support can also be a protective factor against negative outcomes like depression and burden (Saunders, 2003).

The stress process model in a young carer context

Given the use of the stress process model in providing evidence on factors affecting the experience and outcome of caregiving in dementia and severe mental illness, it is important to consider the relevance of the model for young carers of people with SMI..

Exploring a stress-coping-support model in young carers

Pakenham and colleagues in Australia (2007) explored the impact of psychosocial predictors on psychological distress and positive outcomes in young carers. They recruited both from support groups/carer organisations and the general population. The study found social support, particularly satisfaction with social support, to be the strongest predictor of adjustment in multivariate analysis, while coping and choice in caring were also predictive, albeit slightly weaker at the multivariate level. They did not find any demographic variables (age, gender, ethnicity, co-residence, family size, education, employment, number of younger and older siblings) to be related to distress or positive outcomes in their sample. Of other contextual variables examined, only choice in caring was related to outcomes. This suggests that contextual factors had little effect on the stress process in this study. In addition, stress appraisal was only found to be related to outcomes at the bivariate level, but not at the multivariate level. The representativeness and limited statistical power of the study sample also limited their conclusions.

Valiakalayil and colleagues (2004) found that the coping strategies most frequently used by children who had at least one parent with schizophrenia included talking to a sibling, friend or family member, but other strategies like keeping a journal or reflection were also utilised. However, most participants in that qualitative study indicated that more support would be helpful, and particularly requested more information about the illness and more practical skills to deal with their parents' severe episodes (Valiakalayil et al., 2004).

The stressors affecting caregiving in young carers of people with SMI

Initially parental mental illness itself was seen as a risk factor (Cowling, 2004). However, it might be other related factors that act as stressors including caregiving that is long-term or disproportionate, absence of adequate support, impact of social exclusion factors, bullying at school, and loss or grief for a parent (Aldridge, 2011). A SCIE briefing (Parrott et al., 2008) reviewed family-level stressors and resilience factors in parents with mental health problems and their children. Stressors identified included poverty, lack of community support, and aspects of parental mental health such as the effect on parenting, loss, and illness-related behaviour.

The impact of caregiving in children and young carers of parents with SMI

The 2011 Census showed that the percentage of young people aged 5-17 who rated their health as 'not good' was higher among those who provided unpaid care compared with those who did not, and increased with the amount of care provided (ONS, 2013). Studies of the impact of parental mental illness tend to focus on the risk of mental health problems in the children, whether they identify themselves as carers or not. A study in Australia (Cowling, 2004) found that children of parents with mental illness had a prevalence rate of mental health problems that was 2.5 times the norm, according to their score on the Strengths and Difficulties Questionnaire, although this was based on parental report. Spouses of inpatients admitted to acute psychiatric wards in Sweden (Ostman and Hansson, 2002) reported that more than half (54%) their children had further needs for support related to the patient's illness, and these needs were met in about half the cases. Somers (2007) found little difference between children of parents with schizophrenia and matched controls on most lifestyle variables. Parents with schizophrenia reported significantly more problems at school and strange behaviour in

their children. However, the sample was not large and data on the child was collected from the parent. However, qualitative accounts from the children indicated an emotional impact, e.g. feelings of sadness or fear. The issues of blame and stigma are familiar ones in children of parents with affective illnesses (Cogan et al., 2005).

The support needs of young carers of people with SMI

Carer organisations and policy-makers have argued for a need to consider the whole family when providing support for people with mental illnesses (e.g. Frank, 2002). Aldridge & Becker (1999) posit that interventions for young carers in general should include assessment of needs of both parents and young carers.

Young carers of people with mental illnesses (severity not specified) need to know "what is happening to their parent, what is likely to happen and why, the likely impact on their own lives, and what part they can play in their parent's recovery" (Cooklin, 2006, p.35), with explanations given at a level that they can understand (Cooklin, 2010). Listening to what young carers have to say and consulting them on their own needs is the most effective way of helping them (Aldridge, 2008).

The findings of one study showed that, in common with adult family carers, young carers believed that recovery or improvement in their parent's mental illness, was one of the best ways for their own difficulties to be reduced (Grant et al., 2008). Similarly, young carers in Aldridge & Becker's research (2003) wanted their parents to be well or to recover completely, to have their expertise recognised and consulted, and to be able to talk openly about their experiences without fear of being separated from their parent.

Children of black and minority ethnic (BME) parents with mental health problems might be less likely to access services, for example, because of perceived discrimination or a lack of understanding of their complex backgrounds. Perceived discrimination might also be linked to feeling excluded from a parent's care and treatment (Greene et al., 2008).

Elf and colleagues (2011) summarise the kinds of support needs amongst young carers of people with mental illness: (i) knowledge-based needs, including understanding mental illness, managing the person with mental illness, and self care, (ii) need for communication, including sharing experiences, advice and feedback, and befriending,

and (iii) the need for outside involvement, including acute relief, structured help, and healthcare commitments. Aldridge and Becker (2003) further emphasize the need for professionals to listen to young carers, particularly to assess the impact of caregiving, for a whole family approach and for more information-sharing and communication between agencies. They also stress the need for all the contributing factors to be considered together, as well as the need for reappraisal, since the situation can change.

Defining the problem and identifying the gaps

Carers are an important source of support for patients, and family interventions have been shown to improve patient outcomes (Pilling et al., 2002). However these studies are focused on adult carers. Aldridge and Becker (2003) suggested a way to assess young carers' needs based on the nature and extent of caregiving responsibilities, the level and availability of support and the level of expressed need, the nature and severity of the parental illness, the level of parental autonomy and expressed need. While they provide a tool for assessing young carers' experiences as a whole, it is only relevant for children of parents with mental illness and does not indicate that there might be other issues for sibling caregivers. Furthermore, the impact of support is also uncertain, since their study only included those who were supported by young carer projects. Newman (2002) has also pointed out the lack of evidence of the impact of support received by young carers.

How these factors fit together and influence outcomes is less clear. For example, the evidence so far indicates that the kinds of support desired by young carers include emotional aspects, such as somebody to talk to, informational support such as information about the illness and practical advice on how to deal with aspects of the illness, but how it can be provided and what difference it might make is uncertain. A SCIE briefing (Parrott et al., 2008) identified the need for more research that involves the personal narrative accounts of children of parents with mental illness, and that would identify resilience factors with a view towards building positive interventions.

One way forward is to develop a theoretical model for this population, that might explain the different factors affecting positive and negative outcomes, and how an intervention that meets their needs might be expected to work. As Pakenham and colleagues (2007) pointed out earlier within the general young carer population, there is

a lack of studies looking at the psychosocial predictors of adjustment in young carers of people with SMI within an established theoretical framework. Much of the work so far has been qualitative and has identified the difficulties and support needs of this population. Research so far has also focused on carers who attend young carer projects. Using the stress process model as a theoretical basis, the experiences of young carers with and without support can be examined.

The research study: aim and objectives

The initial overarching aim of the study was to identify sources of distress in order to develop a pilot intervention for young carers of people with severe mental illnesses (SMI). Existing research in adult carers of people with SMI and other populations of young carers have identified needs and interventions; an exploration of the overlap between those populations and young carers of people with SMI, and the issues that are specific to this population, is important. This study tests how an existing model needs to be adapted in order to provide a framework to develop the intervention, which is an established method for developing an intervention. To achieve this aim, the following objectives were set:

1. To explore the validity and applicability of the stress process model to the experience of young people caring for someone with a severe mental illness.

2. To use the model to identify causes of distress and the impact of support.

3. To identify mechanisms for intervention through existing evidence and new data, within the framework of the theoretical model, which can be tested in further research.

It is important to note that while the study was focused on experiences of caregiving in young carers, the sample only included the retrospective accounts of former young carers or young adult carers.

CHAPTER 2: METHODS

This chapter first describes the methodology for this study: the components and how they are connected. It then describes recruitment, data collection and the analysis. Thus, the initial section details the "way of thinking about and studying social phenomena" (Corbin and Strauss, 2008, p.1), and the latter section describes how the research was conducted.

Setting the paradigm for the qualitative research

An account of the paradigm or theoretical framework on which a methodology is based is helpful in order to understand the methods used and analysis conducted. A paradigm is a set of beliefs that guides action in a research enquiry and is characterized by ontological, epistemological and methodological assumptions (Guba, 1990). Ontology is concerned with the nature of being, and epistemology, according to Guba, specifically deals with the nature of the relationship between the researcher and what is known. Methodology is the way by which the researcher acquires knowledge or answers a research question. Here, the main concern is with the paradigm informing the research inquiry, or what Morgan (2007) describes as an epistemological stance. Some of the main paradigms are described below.

The positivist paradigm believes in a real world that can be studied and measured, and researchers are required to be detached. Positivists have an experimental approach and mainly use quantitative methods to test hypotheses. The post-positivist approach differs slightly by coming from a critical realist ontology (there is an existing reality but it may never be fully known or understood) and an epistemology that views research as making approximations from incomplete data and urges minimum interaction between researcher and subject. Adherents of post-positivism recognize that there may be unknown variables in addition to those known and therefore tend to ask more questions and involve qualitative methods (Lincoln et al., 2011).

Phenomena viewed through a constructivist paradigm are seen as a construct of one's social and cultural background. The aim to understand, the ability for constructs to co-exist, and the intrinsic role of ethics and values are part of this approach. The researcher

facilitates the inquiry process (Guba and Lincoln, 1994). Knowledge depends on how it is constructed in a learner's mind (Bodner, 1986) and each person's perception of phenomena and interpretation of events will be different (Burr, 2003).

In arguing for a constructionist[3] epistemology, Scheppele (1994) writes: "the whole idea of matching descriptions against the world is misleading because it assumes that there is only one perspective, only one point of view, only one ideology, no room for multiple readings, no potential for disagreement" (p. 94). A constructionist approach accepts that there will be multiple perspectives in the observation and interpretation of social phenomena (Sarbin and Kitsuse, 1994). It emphasizes trustworthiness and authenticity in comparison to positivist validity (Denzin and Lincoln, 1994).

A researcher following a 'strict' constructionist approach would have to accept all constructions as being equally likely, accept only the self as real, and approach research without a social context (Sarbin and Kitsuse, 1994). As Sarbin and Kitsuse comment, it would mean risking a "privatized hall of mirrors" (p. 12). A more reasonable constructivist perspective sees concepts and theories as constructed by the researcher from participants' stories, which in turn are constructed as they try to make sense of their experiences to themselves and to the researcher (Corbin and Strauss, 2008). Schwandt (1994) argues that "one need not be an antirealist to be a constructivist. One can reasonably hold that concepts and ideas are invented (rather than discovered) yet maintain that these inventions correspond to something in the real world" (p.126).

The paradigm behind this research

The perspective driving this research - paradigm as worldview (Morgan, 2007) - less traditionally merges a critical realist ontology with a constructivist epistemology. Such an amalgamation of theoretical perspectives makes for an acceptance of both quantitative and qualitative approaches and a recognition of the advantages and complementary nature of both research methodologies. Thus, by this paradigm, although acknowledging the existence of a real world, we may never succeed in fully understanding it, because of the unknown variables involved (critical realist ontology). Knowledge is perceived as frequently constructed within a social, cultural and personal

[3] The terms 'constructionism' and 'constructivism' can be used interchangeably (Sarbin and Kitsuse, 1994a) and have been used as such in this chapter.

background. Moreover, researchers are influenced by their own lived experiences, which in turn, will influence their research (constructivist epistemology), whether they use quantitative or qualitative methods (based on Lincoln et al., 2011).

A mixed approach - dissension or dialogue?

Such a mixed methods approach is neither theoretically impossible nor unusual in practice (see Tashakkori and Creswell, 2007, for example). On the one hand, Morgan (2007) argues that Guba and Lincoln's top-down approach (e.g. Guba, 1990) means that the epistemological and methodological assumptions of a paradigm are determined by its ontological assumptions. Lincoln and colleagues themselves argue that a constructivist approach is incompatible with positivist forms (Lincoln et al., 2011). On the other hand, relativists do not necessarily deny a reality outside of discourse[4] but assert that how and how much of that reality is perceived, is determined by discourse. Both critical realists and relativists are able to distinguish between ontological realism and epistemological social construction (Burr, 2003). Burr provides arguments for a dialectic relationship between construction and reality whereby reality can be constructed by people, but constructions are also limited by material and social conditions.

A shift in perspective: choosing an appropriate approach

In the debate between flexibility in choosing and using qualitative approaches, and a methodology that lacks consistency and coherence, Holloway and Todres (2003) argue for appropriateness: that is, by understanding the purpose and methodology of each approach, the researcher can discerningly choose a methodology appropriate to the research question, with due regard for consistency and coherence. Choosing an appropriate approach would thus depend on the research question, bearing in mind that certain qualitative methods and techniques (e.g. interviewing, thematic analysis) can be generic and span multiple approaches (Holloway and Todres, 2003).

Morgan (2007) argues for a movement from the metaphysical paradigm advocated by Guba and Lincoln to a more pragmatic approach. He proposes a focus on the methodology related to the research, with equal attention given to its connections with

[4] A discourse is a set of statements, images, representations, etc. that creates a particular perspective (a version) of an object. The object is constructed by its description (Burr, 2003).

epistemology and methods. He also emphasizes the importance of the researcher's worldview, since it enables reflexivity about the choices and assumptions one makes with the research, including the influence of one's own values and beliefs. Johnson and Onwuegbuzie (2004) posit that quantitative or qualitative methods or both together can be used, depending on appropriateness, since both have their merits, thus making a case for a needs-based approach to using research methods.

Thus, based on the argument for choosing an appropriate approach, an epistemologically constructivist perspective (i.e. a perspective that identifies knowledge as being constructed from one's experience) was seen to be appropriate for this research question. The aim in this thesis is to understand young carers' experiences within the framework of the stress process model, and the expectation is that their experiences are likely to be affected by contextual factors. Each person provides a unique perspective and the researcher, as somebody with some similar experience, brings her own perspective to the research.

Research design

The introduction to the study in the previous chapter has provided the background to this research area and indicated the gaps in the literature. From that and the theoretical perspective just outlined, the research question and the research design have been delineated. The aim of this study was to understand the experience of young carers looking after someone with a severe mental illness within the context of the stress process model, and to identify mechanisms for intervention. The need for an evidence-based intervention, and the Medical Research Council (MRC) guidance for the development of complex interventions (MRC, 2008), was an important influence. Although there is some (mainly qualitative) research in this area, exploring young carers' experience within a theoretical framework has the potential to support and add to the existing literature, and to develop a subsequent intervention

MRC guidance for complex interventions

It is anticipated that an intervention for young carers is likely to be complex, comprising "several interacting components" (MRC, 2008, p.6). The key message in the MRC framework is the need for an understanding of the processes and mechanism of an intervention in order to be able to fully assess its effectiveness (Campbell et al., 2007).

The 2008 guidance is an updated version of the MRC framework published in 2000 (MRC, 2000), incorporating a model that is more flexible and less linear than the one in the earlier guidelines, as well as case studies to serve as practical examples (MRC, 2008). The guidance posits the importance of the developmental and piloting stages in order to generate a sound and useful intervention. Campbell and colleagues (2007) suggest that understanding the context for the intervention is crucial, both for developing the intervention and for its generalisability. A theoretical understanding of the levels of complexity might also help to identify factors mediating the effectiveness of the intervention on the selected outcomes.

According to the MRC guidance (2008), the process from development to implementation of a complex intervention goes through four main stages, although a research project may move between stages in a non-linear fashion. The *development - feasibility/piloting - evaluation - implementation* process suggests systematic movement through each phase but allows for the need to return to a previous phase.

This project was based on the development phase. The three main elements of the development phase are: (i) identifying the evidence base, (ii) identifying/developing appropriate theory and (iii) modelling process and outcomes (MRC, 2008). A systematic review of research literature was used to identify an evidence base for interventions for this population. The second part involved identifying existing theory and adapting it to the young carer context. The third part, modelling process and outcome, using new data from a sample of former young carers, was completed using qualitative research methodology. The only stage that was not attempted was modelling process and outcomes using quantitative methods.

Systematic review

The need for a systematic review of the literature stems from clinical and policy decision-making that is based on a number of sources of information and the expectation of evidence-based health care (Mulrow et al., 1997). Systematic reviews reduce large quantities of information that have not yet been assessed to manageable evaluated portions (Mulrow, 1994). In their role as synthesizers of the results of treatment trials, systematic reviews form what Mulrow *et al* describe as “a vital link in the great chain of evidence that stretches from the laboratory bench to the

bedside" (Mulrow et al., 1997, p.390). They are useful to decision-makers, specialist analysts, researchers, healthcare providers and policy-makers in preventing the use of resources on researching or implementing treatments that have been shown to be unnecessary or ineffective. They can shorten the period between discovery and implementation; for example, by pooling the findings of all existing trials a cumulative meta-analysis could show a treatment to be effective earlier, reducing the need for a large number of trials. Furthermore, systematic reviews enable generalisability, assessment of consistency and explanation of inconsistency, and increase power and precision (Mulrow, 1994).

The purpose of a systematic review is to collate systematically evidence that matches explicit *a priori* criteria in order to answer a research question. It uses specific methods to minimize bias and increase the reliability of the findings from which conclusions can be drawn and decisions made (Green et al., 2011). The findings may be synthesised using quantitative methods, in order to provide a more precise estimate of the effect of an intervention, and this final stage of a systematic review is termed a meta-analysis (Liberati et al., 2009). As indicated by the above definition, for a review to be systematic

• the objectives need to be clearly stated and the eligibility criteria for inclusion/ exclusion of studies need to be defined *a priori*

• the methods used need to be clearly detailed and reproducible

• the literature search needs to be systematic and attempt to find all studies that could be eligible

• the included studies need to be evaluated for their validity

• the characteristics and findings of the included studies need to be systematically synthesised and presented (Green et al., 2011).

The key point is that systematic reviews try to find 'the whole truth', i.e. they attempt to find all the evidence relating to that specific research question (Mulrow et al., 1997).

Narrative synthesis

Guidance on the conduct of narrative syntheses suggests that this method can be useful when a systematic review includes a number of different study types. Far from being a 'second-best' method, it is suggested as an initial step before a meta-analysis, may add theoretical insight to the topic under research, and can be used as a method for the synthesis of evidence on effectiveness of interventions (Popay et al., 2006). A narrative synthesis brings together the evidence from multiple studies and moves beyond their findings to generate new insight and knowledge (Mays et al., 2005). A narrative synthesis was chosen as the method of synthesis for the systematic review, when a meta-analysis was not feasible, because the studies included had dissimilar research designs. This approach is in keeping with the aim of the systematic review to summarise the research evidence and to build theory and explanation from the evidence. It can be used with both quantitative and qualitative evidence (Mays et al., 2005).

Mays *et al* (2005) posit that qualitative and quantitative studies should be able to be integrated in a systematic review by the same logic that sees them working side by side in mixed methods research, although the methods for doing this are less developed. They further argue that synthesizing qualitative and quantitative results in a systematic review is more akin to subtle realism than relativism. Integrating qualitative and quantitative studies in a systematic review is in keeping with the researcher's pragmatic approach outlined earlier.

A systematic review of existing interventions using a narrative synthesis to analyze the results, was concordant with the qualitative approach.

Traditional qualitative methodological approaches

Braun and Clarke (2006) divide qualitative methodological approaches into two categories: those that are based on a particular theoretical epistemology and those that are less dependent on theory and can be applied across different epistemological approaches. Of the former, some approaches have more freedom in how the methods are applied. Two frequently used qualitative approaches - Interpretative Phenomenological Analysis (IPA), and Grounded Theory - will be detailed below. While there are a number of other qualitative methodological approaches (e.g. participatory action research, ethnography) these two approaches were the main

contenders while deciding upon an appropriate methodology for the research, because these approaches have been widely used in qualitative studies of health services, including studies of carers of people with mental illnesses (e.g. Lawrence et al., 2008, Whitney et al., 2012). However, a third approach, that is growing in popularity in its own right, was also considered, and the reason for choosing it over other approaches is given below.

Grounded theory, as a qualitative methodology propounded by Glaser and Strauss (1967), is based on the "discovery of theory from data systematically obtained from social research" (p.2). Rather than testing an existing hypothesis or theory, it is used to explain a process by developing theory through careful analysis of the data (Lingard et al., 2008). The appeal of grounded theory lies in its systematic yet creative working strategy (Pigeon, 1996).

The key characteristics of grounded theory are the emphasis on the development of theory that is 'grounded' in the data and the following guidelines and tools for systematic analysis (Glaser and Strauss, 1967, Charmaz, 2006):

Coding: Early analysis of the data involves giving each segment of data a label that is characteristic of its meaning.

Theoretical sampling: In contrast with random sampling or representative samples, theoretical sampling seeks participants who will expand or delimit existing themes (patterns in the data).

Constant comparison: New codes and themes from each case are continually compared to other cases and to earlier coding in order to refine the coding framework, with a continuous movement towards more abstract concepts.

Theoretical saturation: The point at which new data about a theme adds no further insight to the developed theory.

Theoretical memos and diagrams: Theoretical memos are a constant writing process that takes place throughout the analysis as the researcher records her ideas about the data and emerging codes, identifies connections and progresses to new abstract concepts.

These systematic methods for qualitative analysis helped to contest the positivist notion that qualitative research was unsystematic, impressionistic and biased, and that quantitative scientific methods were the only method of acquiring knowledge (Charmaz, 2006).

Interpretative Phenomenological Analysis (IPA) aims to understand a person's lived experience from that person's perspective. "The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p.40), making IPA both interpretative and phenomenological respectively. It aims to capture the essence of the lived experience both in a general and contextual sense. In the analysis, the researcher moves between the meaning of the component parts of the text and the whole meaning of the text. Similarly, the results communicate the essence of the experience as well as the different aspects or characteristics of the experience. In contrast with a Grounded Theory approach, IPA steers clear of causes and explanations, although plausible interpretations can be offered (Holloway and Todres, 2003).

An introduction to thematic analysis

Thematic analysis is a qualitative research method that involves the search for and identification of common patterns or themes in qualitative data (Morse and Field, 1995). While thematic analysis is commonly used in the initial stages of other qualitative methods of analysis, and has been propounded as a process in different methods (Boyatzis, 1998), more recently it has been argued that thematic analysis is a distinct qualitative method in its own right (Braun and Clarke, 2006). Thematic analysis involves the organisation of the data set, its description in rich detail, and development of further interpretive understanding of the topic (Braun and Clarke, 2006).

A theme captures something essential, is related to the research question, and is indicative of a pattern or common response or meaning across the data set (Braun and Clarke, 2006). Morse and Field (1995) also write of themes as "significant concepts that link substantial portions of the interviews together" (p.140). Themes are often abstract (or latent) and not immediately evident. They might be indicated by the data rather than directly described by the participant (Morse and Field, 1995). DeSantis and Ugarriza (2000), in their review of the use of the term theme in qualitative research, also

summarise themes as implicit or implied, but supported by distinct occurrences in the data. Braun and Clarke (2006) confer the onus on the researcher to decide whether the themes to be identified will be semantic (i.e. manifest) or latent (i.e. interpretive) and Boyatzis (1998) further argues that thematic analysis can incorporate both at the same time.

Analysis involves the development of inductive (developed from the data) or deductive (predefined categories applied to the data) themes, frequently moving between both kinds in one analysis. Early codes may be labelled in language similar to that used by participants, and early coding tends to be as inclusive as possible, with chunks of data assigned multiple codes. Related or similar codes are then grouped to form themes, which helps to refine, reduce and select categories for further investigation. A more in-depth thematic analysis will then involve looking for links between the themes, which might be obvious, or which might involve asking questions of the data and examining the influence of different factors (e.g. gender) (Pope et al., 2006).

Choosing thematic analysis over other approaches

Thematic analysis is compatible with both positivist and constructivist paradigms, not being attached to a particular theoretical approach (Braun and Clarke, 2006). This theoretical flexibility is one of its advantages, given the researcher's theoretical perspective discussed earlier. Thematic analysis would allow the use of both focus groups and interviews as triangulatory methods of data collection, something to which IPA, for example, with its focus on depth of experience (Holloway and Todres, 2003), might not be conducive.

Grounded theory seemed a useful method insofar as it incorporates participants' own accounts of events and their associated contexts (Pigeon, 1996) and utilizes tools for systematic and rigorous qualitative research. The aim of the study, however, was not to develop a theory - as defined by grounded theory methodology - about young carers, but rather to adapt existing theory for this population. This meant that the researcher could not approach the analysis with an unbiased mind, since existing theories and literature had already been considered. Moreover, some aspects of Glaser and Strauss's methodology suggest a positivist epistemology, particularly with respect to the researcher's role; for example, when describing theory as being 'discovered' or

'captured' by the researcher (Pigeon, 1996). This objective approach does not take into account the context and philosophical stance that the researcher brings to the analysis or the researcher's interpretation of the data (Charmaz, 2006). Arguments have been made for viewing Grounded Theory from a constructivist perspective (Pigeon, 1996, Charmaz, 2003) by using the analytical methods of Grounded Theory rather than the methodological approach overall (Charmaz, 2006). Thus, thematic analysis was the chosen method of analysis with the additional use of Grounded Theory techniques to increase rigour.

Incorporating elements of Grounded Theory

Holloway and Todres (2003) have suggested that grounded theory techniques can be used in other approaches. Incorporating elements of Grounded Theory would support the systematic analysis of data using methodical procedures. While the ways in which these techniques were used in the present study have been described in the methods section, the different terms are expanded below.

Memo-writing is an important grounded theory tool in which the researcher keeps a written record of theory development throughout the data collection and analytical processes. The widening and narrowing definitions of themes, the labels chosen for them, their inter-relationships, the researcher's reflections and changes in direction of the analysis are recorded in the memos. They can be written (or drawn) in the way most suited to the researcher (Willig, 2008). Memo-writing enables storage and retrieval of analytic progress, facilitates new ideas and connections and helps to fine-tune results.

The analysis also aimed for theoretical saturation although, as Glaser and Strauss (1967) have pointed out, the differing relevance of each theme to the research question means that not all themes will be explored to the same extent. According to Glaser and Strauss, theoretical saturation depends on the empirical limits of the data, the researcher's theoretical sensitivity and the developing theory reaching a certain level of integration and density. Saturation is achieved by studying several sub-groups, maximising differences between them and comparing different situations, a technique known as theoretical sampling. Theoretical sampling involves collecting new data with reference to previously identified themes (Willig, 2008). An adequate theoretical sample would have sufficiently diverse sub-groups for saturation of the critical themes in the theory

(Glaser and Strauss, 1967). Theoretical sampling of sub-populations or events that will confirm or elaborate emerging theory allows the theory to be checked (Willig, 2008).

Constant comparison involves comparing the similarities and differences between themes and comparing newly identified themes with existing themes in order to delimit and define the themes in the coding framework. Once a theme has been defined, constant comparison also enables identification of codes within the theme by focusing on the differences within the theme (Willig, 2008). Theoretical sampling, theoretical saturation and constant comparison are all part of an iterative study design where data collection and analysis occur cyclically, with analysis informing the next phase of data collection to refine the developing theory (Lingard et al., 2008).

A stakeholder perspective

Involving stakeholders in health services research, policy and provision has been given more importance recently, but the level of involvement can vary. The benefits can include learning from service users and carers, asking more relevant research questions, and valuing their perspectives, but the actual impact on services is less certain (Minogue et al., 2009). Although involvement can be nominal or limited to stakeholders merely participating or being engaged (INVOLVE, 2012), this research study was intended to empower the stakeholder/carer in deciding what was important and in directing the focus of the research. This shift in control from organisation to stakeholder is debated for its impact on research direction, but it has also been argued that stakeholders are unlikely to focus on an area that is not a priority, given their own experiences (Minogue et al., 2009). Using qualitative methods, focusing on a needs-based approach, involving young carers in deciding what was important to them, are all examples of where the research was controlled by the stakeholder/carer/researcher. However, this also requires checks to be put into place to ensure that the goal is not personal reward or empowerment: most importantly, reflexivity, but also supervision and joint coding of interviews.

A stakeholder perspective (i.e. carer-led research) also connects the constructive epistemology with the pragmatic needs-led methodology. Rose *et al.* (2006) have highlighted the constructivist approach to user-led research because of the multiple

perspectives contributing to building evidence-based policy. The dearth of carer-led research is an important gap in the young carer literature and a focus for future research.

Research ethics

Approval of the research study

Before recruiting participants, an application was made to the then Ealing and West London National Health Services (NHS) Research Ethics Committee (REC). The application was made to an NHS REC rather than the King's College London (KCL) REC on the advice of staff at the Institute of Psychiatry, Psychology and Neuroscience (IoPPN) because, in spite of there being limited contact in the study with the NHS, it was hoped that some participants might be recruited through mental health services and therefore NHS research ethics approval was required. This researcher attended the review meeting in December 2009 and answered questions from the REC. After making the requested changes to documents, approval for the study (REC Reference number 09/H0710/65) was granted in January 2010.

An application for Research & Development (R&D) approval from the South London and Maudsley NHS Foundation Trust (SLaM) was made via the IoPPN R&D office with a request initially made for involvement of one SLaM Directorate (Lambeth Borough), which was later extended to include two more Boroughs (Lewisham & Croydon). Later still, when the structure of the Trust was changed to Clinical Academic Groups (CAG) according to disorder type, a request for approval was made to include the Psychosis CAG. In order to involve each of these Directorates/CAGs, a request for approval first had to be made to each Service Directorate Manager and was duly obtained. R&D approval (Reference number R&D2010/014) on behalf of SLaM was received in February, 2010.

The REC (which, following restructuring to the National Research Ethics Service, became North London REC 3 and then NRES Committee London-Harrow) was contacted for advice on whether any changes were minor or substantial amendments before changes were made. The only substantial amendment was made in June 2011 for which approval was granted in July 2011. The study protocol was amended to incorporate interviews and small focus groups with young carer project workers in order to examine the feasibility of the suggestions for interventions made by participants,

given the experience and expertise of the project workers. Also, instead of discussing potentially relevant outcome measures with young carers in a second wave of focus groups as previously planned, it was decided to explore outcomes with the nominal group. Based on the interviews conducted, it was felt that this would be more effective, informative and feasible.

Ethical issues considered

The sample could be considered vulnerable for two reasons: some of them were aged under 18, and all of them had personal circumstances with potential emotional and psychological implications. The main ethical issues to be considered were safeguarding, voluntariness of informed consent, and discussion of distressing experiences in some cases. While none of the participants was aged below 16, some of them were under 18 years old. Parental consent, therefore, was not a requirement, but all participants provided informed consent before taking part. Recruitment was mainly through their young carers project or by advertisement, ensuring that consent was voluntary. The only person to contact the study through the (then) South London & Maudsley NHS Trust refused consent when provided with full information about the study. Data collection took place either at their young carers project or at the Institute of Psychiatry, to ensure their safety. Furthermore, most of the participants under 18 took part in the focus group, at which their own support workers were present.

Given their personal circumstances, it was anticipated that talking about their experiences might be distressing for participants, although the researcher would try to be as empathic as possible and had experience of being a young carer herself. If a participant still showed signs of being distressed at the end of the interview, the researcher would consult her second supervisor, an honorary consultant clinical psychologist, for advice. Participants were contacted afterwards to check if the interview had been distressing for them. Most participants responded positively to the experience and none indicated subsequent distress.

The vulnerable nature of the population was the main reason for using a sample of former rather than current young carers.

Consent forms and questionnaires were stored in a locked cabinet and digital recordings were stored in a password-protected folder. Transcripts were anonymized, i.e. any

identifiable information was removed, and participants were first assigned numbers and then given pseudonyms. All personal data was kept confidential and limited to the research team. Participants were informed that anonymized transcribed data might be used in publications and for teaching purposes.

All participants were provided with information sheets (see Appendix 2.1) before the interview and were asked if they had any questions, before they signed the consent form (see Appendix 2.2). The researcher also signed the consent form and the participant was given a copy to keep. Participants were told that they did not have to take part in the study and that they were free to withdraw at any time. If they chose to withdraw from the study, their data would be removed from the study. None chose to do so.

Participants were given £10 vouchers (from Amazon in most cases) to compensate them for their time for each interview/focus group and travel expenses were reimbursed.

Recruitment

Participants were recruited through three main routes

- advertisements in the South London and Maudsley (SLaM) NHS Trust

- contacting carer and young carer organizations

- advertisements in King's College London (KCL) and the Institute (IoPPN)

It was felt to be important to have different methods of recruitment because most of the research in this field before this study began, had recruited only through young carer organizations. Thus, most of the research was based on the perspectives of those who were already receiving support of some form. This researcher felt it was important to tap into the experience of the hidden population of young carers who had not received support during their experience. However, there are difficulties with accessing children through their parents in mental health services since adult services do not tend to come into contact with children and parents might not view their children as carers or be willing to accept their caregiving role. It was considered not feasible to use these participants in this study.

Advertising through SLaM was not very successful, partly because of the difficulty of different approvals required, partly because of the researcher's unfamiliarity with the

NHS system and partly because the Trust was undergoing structural change at that point. Accessing young carers through their parents receiving services in SLaM was also difficult because adult mental health services do not tend to prioritise their clients' children. In the meantime, advertising through other routes proved more successful. More than 60 carer and young carer organizations, groups and projects across England were contacted by telephone and email to ask if they were in contact with any eligible young people who might be interested in taking part. Finally, the study was advertised through websites linked to the IoPPN, posters were placed around the College, and emailed to all staff and students once it was approved by the KCL Research Ethics Office.

This last route was initially the most successful as it provided the first participant for the study. On feedback from that interview and the pilot interview, the wording of the poster was amended. Initially it had asked young carers to contact the researcher (see Appendices 2.3 and 2.4) but on the advice of both the pilot participant and the first participant, it was amended to say "Does someone in your family (for e.g. parent/ sibling) have a severe mental health problem? Have you helped look after them? Are you 16-25 years old?" and sent out again, and the improvement in response was noticeable. This highlighted the fact that young carers, as with older carers (e.g. HM Government, 2008), do not always recognize themselves by that term or possibly even by that role.

Sample

Participants in the study were young people aged 16-25 years who identified themselves as former young carers or current young adult carers[5] (both primary and secondary[6]) of someone with a severe mental illness. While the definition of young carers is limited to those under 16, it was decided to recruit participants aged 16 and above, so that they could look back and reflect upon their experience as young carers and provide a retrospective perspective. While children can be active agents in research, with

[5] The difference between young carers and young adult carers has been discussed in the background to the study; some of those recruited were continuing to provide care as young adults

[6] The term primary carer refers to the main caregiver or the person with the most caregiving responsibilities, while secondary carers are those who provide care in addition to the primary carer

information sought directly from them, it was felt that retrospective accounts would provide more understanding of the changes in their experience over time, and their perceptions of what had contributed to positive and negative outcomes. Although legally children are considered to be below 18 years of age, the NRES treats those under 16 differently in terms of their ability to provide independent informed consent. This was an important distinction, considering the study's volunteer sample.

Initially, it was decided that they would need to identify themselves as young carers, but when this was found to be a deterrent, participants who identified themselves as helping to look after someone with a severe mental illness were invited to contact the researcher.

The initial exclusion criteria were

1. young carers of people with substance abuse problems alone.

2. people without an adequate command of (ability to converse in) English

Once the study had begun, it was found that young people caring for people with dementia and learning disabilities were also contacting the researcher. This was not envisioned in the study's definition of severe mental illnesses (see Chapter 1) and these potential participants were also excluded. Finally, the need for a volunteer sample for this research meant that the self-reported diagnosis could not be verified without access to the patient or to case records.

Sampling

"An appropriate sample size for a qualitative study is one that adequately answers the research question" (Marshall, 1996). An important feature of qualitative research is the small samples that are studied in context and in great detail (Miles and Huberman, 1994). Maximum variation sampling takes place when one tries to sample as wide a range of perspectives on the subject being researched as possible and it is useful for finding both the uniqueness of each case or sub-group as well as the common themes that occur despite the diversity (Kuzel, 1992, Patton, 2002). Since the study sought to understand the range of experience of young carers, we aimed to recruit participants of both genders, from different ethnic backgrounds, caregiving relationships and caring for people with different SMIs. Thus sampling was purposive, with a particular focus on finding and including former young carers who had not received support from young

carer projects. However, the difficulties with a variant sample need to be considered, chiefly whether there is sufficient commonality of experience to produce findings that are useful, and this will be seen in the results.

Given that it was mostly a volunteer sample, theoretical sampling was not possible at a level where participants were actively sought to expand on emerging themes but the researcher actively attempted to explore themes of interest as recruitment continued. For example, most participants were caring for a sibling or a mother with SMI. It was felt to be important to include the perspective of somebody caring for a father with SMI and one such participant was interviewed. A former young carer who had experience of representing young carers and speaking at events across the country was invited to participate, because it was felt that he could provide an overview of the work being done for young carers currently and the gaps in support.

Data collection

Rationale for the choice of methods

The methods of data collection most appropriate to the theoretical perspective and research design detailed above were deemed to be a combination of interviews and focus groups. Interviews were the main method of data collection, since they could provide an in-depth, detailed understanding of the experience of selected participants. They would also be helpful for participants who found it difficult to talk about their personal experience in a group setting or for pursuing stories of particular interest. However, since a focus group could provide a holistic perspective from the opinions of several participants, and their discussion could broaden and expand understanding, a focus group was also utilised. This fits in with the pragmatic constructivist approach described earlier, since recognition of multiple perspectives was combined with a need for common understanding.

Interviews

An interview can be described as a conversation directed by the researcher's information needs (Green and Thorogood, 2004). It focuses on the participant's experience and beliefs, with the researcher's questions aiming to encourage participants' narratives. The researcher guides the interview in the right direction and, at

the same time, is alert to a need for flexibility when a participant introduces a new topic of importance (Willig, 2001). The interviewer listens and observes, encouraging the participant to reflect on his/her experience and related issues in a way that might not occur ordinarily (Charmaz, 2006). As a method of data collection, interviews can be used with a range of analytical methods (Willig, 2001). Individual interviews were also found to be logistically easier and more suited to the sensitive nature of the topics discussed (see *Change in protocol* below).

The interviews were semi-structured, balancing direction from the researcher towards topics of interest, and freedom for the participant to bring up issues they considered important (Willig, 2001). To this end a topic guide was created listing the main topics to be covered with examples of probe questions that could be used (see Appendix 2.5) based on existing literature. They were in-depth, in that participants were given enough time "to develop their own accounts of the issues important to them" (Green and Thorogood, 2004). The researcher could probe participants' statements and ask participants to reflect on how particular situations or experiences had made them feel (Charmaz, 2006).

All interviews were conducted by the researcher at the IoPPN or at young carer organizations and were planned to take approximately an hour, although occasionally this extended to an hour and a half. The topic guide was piloted with a researcher with previous experience of being a young carer in a different country, which also provided the researcher with an opportunity to practise her interviewing skills. It was amended further after discussion with a fellow researcher with previous experience of being a young carer in the United Kingdom.

Both the pilot interview and the interview with the first participant were helpful in refining the topic guide. For example, the researcher at first felt that it might be useful to mention her own experience of caregiving to facilitate rapport but realised that it then tended to determine the course of the interview, which was unhelpful and not in keeping with good interview practice. After discussion with her supervisors, it was felt that it would be better not to describe her own experiences in the interview, since it had already been mentioned in the study recruitment material, unless a participant asked about it, in which case it could be discussed after the interview to avoid influencing the interview altogether. Legard and colleagues (2003) explore this debate, recognizing the

difficulty that interviewers face in not revealing themselves, and come to similar conclusions.

While sampling depended on participants making contact with the researcher and therefore it was difficult for data collection and analysis to be conducted iteratively, the topic guide was amended iteratively, exploring new themes of interest from the previous interviews (see Appendix 2.6). The questions in the interviews progressed from generic questions about the young carer, the person for whom they provided care and the illness, to specific questions about their views, advice for other young carers, and potentially beneficial interventions. The interview incorporated what Legard and colleagues (2003) term "concept mapping" (questions that open up topics of interest) and "concept mining" approaches (questions that explore those topics in greater detail) (p.148).

Focus group

Willig (2001) describes a focus group as "a group interview that uses the interaction among participants as a source of data" (p.29) and suggests that this method enables the researcher to explore jointly constructed meanings in more natural settings than one-on-one interviews. The group context might enhance disclosure due to participants asking more searching questions of each other, disagreeing or contradicting each other. Wilkinson (2004) asserts that focus groups might not be inhibitive for personal topics and the group context might facilitate disclosure, and Silverman (2004) extends this by arguing that qualitative interviews need not be seen as the gold standard method of providing insight into people's experiences. On the other hand Willig (2001) contends that individual interviews might be more appropriate for topics of a sensitive nature. It was felt that a focus group might produce more holistic data through debate and discussion.

The focus group consisted of members of the same young adult carer project. Many of them had met before, and the participants shared a key experience as former or current caregivers (Willig, 2001). The group had been convened through the young carer project and the researcher had no contact with the participants or information about them before the discussion took place. At the focus group, the researcher found that one of the young adult carers who appeared to meet the eligibility criteria was caring for her partner, which was different from the relationship of the other former young carers..

Therefore the researcher was careful to ensure that any new themes that came from her account were supported by other participants in the analysis, i.e. there were no themes discussed in the findings that had only come from this young adult carer. The focus group took place at the young adult carer project and was conducted over three hours. Participants were given a break in between and provided with refreshments. The researcher was not accompanied by a trained co-facilitator but two of the young carer support workers were present. A few of the young adults found it difficult to engage in the discussion because they felt it was depressing. However, one of the support workers was able to engage with them separately during the break and the researcher worked to balance the discussion by focusing on more positive aspects after the break. All the participants were able to contribute to the discussion.

There were also two focusing exercises planned and conducted during the discussion: one where the participants had to provide words or phrases that came to mind when thinking of their previous experiences which were written by the researcher on a flipchart, and the other where they had to write things that they liked and disliked about being a young carer on differently coloured post-it notes. These were then arranged on a sheet with the help of the participants. The initial plan had been for the participants to categorise the results themselves, but time and logistical constraints - such as the size of the focus group and the table - required the researcher to arrange the post-it notes on the advice of the participants. The exercises not only added to the data from the group, but also gave everybody a chance to be involved.

Methods for refining the interventions

For the second part of the qualitative study, a nominal group was selected as the method for refining the earlier suggestions for interventions, in which the results were fed back to a smaller group of existing participants who could discuss, and qualify the suggestions made for interventions. Interviews with support workers were also used in the second part of the study to determine feasibility and identify barriers and facilitators for interventions, based on their experience of working with this population. Qualitative methods like the nominal group and support worker interviews were useful because they permitted the further understanding of process and outcomes advised by the MRC guidelines (2008), although a quantitative pilot study will be essential later.

The nominal group is a consensus method (Fink et al., 1984), used to agree on a possibly beneficial intervention, given the views of the other young carers in the focus group and interviews. The nominal group method has frequently been used to examine the appropriateness of interventions, and has been used with this population before (see, for example, Graham et al., 2014). The strength of a nominal group, as with a focus group, lies in the discussion where differing opinions can elaborate the barriers and facilitators to a suggested intervention.

Other qualitative techniques

Theoretical saturation

The issue of theoretical saturation is considered to be more important in qualitative research than having a large sample. However different qualitative experts have pointed out this should be seen as a goal rather than a mandate (Willig, 2001) since qualitative research, by definition, is sensitive to perspective and perspectives will always differ slightly. While recruiting and interviewing participants, the researcher felt that saturation had been reached when the topics covered were bringing out similar responses to those already given. Indications of saturation, such as repetition and confirmation of previous results (Morse, 1994) could be seen in the last few interviews. The researcher then discussed this with her supervisor who agreed that saturation might have been reached. Finally, after coding the interviews, the researcher went through the themes from the last interview to confirm that no new themes had arisen.

Reflexivity

The researcher aimed to be reflexive by considering her own position in the data analysis (Macbeth, 2001). Since the researcher had been a young carer herself, her influence on the study needed to be taken into account in the fieldwork and analysis. It was felt that her experience would help with rapport-building in the focus groups and interviews and would help to keep the study relevant to young carers (INVOLVE, 2012, Minogue et al., 2009). However, this also made reflexivity indispensable in ensuring that her experiences did not overshadow participants' stories.

Willig (2001) describes this kind of reflexivity, which she terms personal reflexivity, as involving both reflection on the influence of the researcher's values, beliefs, and

ideologies on the research, as well as reflection on the impact of the study on the researcher. In practice, this meant being aware of both the relevance of the researcher's own experience and the differences in experience, and using theoretical memos to reflect on the effect of own experience on the analysis. Doing the research was also a learning experience as the researcher listened to other people's experiences and found similarities or insights into her own.

The issue of power is an important one, because the views and experiences of the researcher, especially in a stakeholder-led study, cannot be imposed on participants. One of the ways in which this was addressed was by consciously avoiding discussion of the researcher's experience during the interview/focus group discussion. Theoretical memos were also an important tool in the analysis to identify where the researcher might have been imposing her view on the analysis. However, the researcher's experience was also an advantage as discussed earlier, and its experience could be seen in other ways: the focus on needs-based research, on young carers' perspectives, on the potential for positive outcomes through the stress process model, and on the need for evidence-based interventions to support this population. Power is a difficult balance in a thesis because of the need for it to be the researcher's own work (Etherington, 2007). A constructivist epistemology and qualitative methodology enable the researcher to seek to construct understanding and knowledge together with participants.

Reflexivity on the part of the researcher in this study has also involved moving from the notion of objectivity to the recognition of the subjective experience and being transparent about the same. It has involved opening oneself to the reader and being vulnerable to the risk of being exposed (Etherington, 2007).

Combining data sources

Combining data from different sources and by different methods was used as a validation strategy (Flick, 2004). Since the sample size was small, combining two different methods of data collection - the focus group and interviews - helped to strengthen the analysis and findings. Combining data methods was chosen because each type of data source provides a different perspective on the topic, e.g. focus groups provide jointly constructed meanings and expand understanding by discussion and debate. In practice, this meant that the findings from the interviews and focus group

were initially coded and analysed separately, before being brought together in the adaptation of the stress process model, which would enable identification and exploration of differences.

By including different sources, the researcher hoped to get a more comprehensive perspective of the topic (Miller and Fox, 2004). This can confirm concurring findings or highlight divergent results which can then be explored and understood. If the two kinds of sources capture different things, the researcher can try to understand the differences (Patton, 1987). The nominal group was seen as a method of member-checking[7], in which the types of support requested by participants were fed back to a smaller group of participants, discussed and prioritised. The interviews with support workers were aimed at identifying potential barriers and facilitators of the suggested interventions.

Analysis

All the interviews and the focus group discussion were recorded on a digital recorder with the permission of the participants. Audio recording allows the researcher to give full attention to participants without the distraction of note-taking, and provides a full verbatim account of the interview/focus group (Willig, 2001). The data were transcribed verbatim and checked by the researcher for accuracy.

Thematic analysis was used to analyse the data and categorize recurring themes. The intention was to identify common themes in the individual narratives. The researcher went through each transcript, first coding the entire transcript descriptively, and then categorising and grouping the codes into themes, comparing narratives to identify recurring themes. Each transcript was initially coded on paper and then coded using NVivo, a software package for qualitative data analysis (QSR International, 2010, version 9) which facilitates coding and organisation of the data. The themes were reviewed and the coding for earlier transcripts was updated.

The first step was to provide a rich description of the data set and the research topic (see appendix 2.7). Both semantic/descriptive and latent/conceptual themes were identified throughout the process (Braun and Clarke, 2006). These inductive themes were then

[7] Member checking is a form of validation in qualitative studies by comparing the researcher's analysis and interpretation with participants and incorporating their reactions into the findings (Mays & Pope, 2000)

examined for fit with the stress process model for caregiving. Memos and diagrams (Strauss and Corbin, 1998) were used to help the researcher maintain a record of thoughts, observations, progress and conceptualizations during the analytic process. This was an exercise in restructuring and re-organising the data with the help of tables (see, for example, Appendix 2.8), and referring to the original NVivo coding for additional clarification and references. The analysis was seen as being hybrid in nature (Boyatzis, 1998), being both inductive, but also including theory-driven deductive analysis, e.g. searching for text that was consistent with elements of the stress process model.

Validation of the themes occurred in three ways:

(i) some of the initial transcripts were independently coded by the researcher's supervisor and the themes were compared and discussed and discrepancies resolved,

(ii) a different transcript was independently coded by another researcher and themes were compared and discrepancies resolved by discussion, and

(iii) the coding framework was applied independently by the supervisor to a transcript and, again, this was discussed, and changes made where this was found to refine conceptual understanding.

This helped to ensure that the researcher's identification of themes was not just idiosyncratic. Additionally, this researcher was able to consult another young adult carer researcher and compare notes from that discussion with her own data.

Change in protocol

Qualitative research is not a linear process and therefore, on the basis of early fieldwork, it was felt to be more informative to amend the original protocol to build theoretical understanding by interviewing young carer support workers with whom the study had already been in contact. It was also felt to be more feasible and appropriate to explore outcomes of potential relevance with the nominal group, instead of validating measures with a second wave of focus groups. From the themes identified in the initial analysis, it was felt that the outcome measures proposed to be validated were no longer as relevant as they were initially thought to be, and discussing potentially relevant

outcomes with the nominal group was likely to be more helpful. A substantial amendment was made and approved by the REC to this end in July 2011.

One of the initial aims when the study was being developed was to conduct a pilot study for modelling process and outcomes but this was felt to be beyond the scope of the thesis, given all the other elements involved and the difficulties with finding young carers. Thus it was decided that modelling of process and outcomes would take place using qualitative methods, i.e. the nominal group and interviews with young carer support workers.

Summary

This chapter has discussed the process of selecting the methodology appropriate for the research question, including the underpinning theoretical perspective, the research design, and the methods of data collection. Driven by a pragmatic approach and a constructivist epistemology, the choice of qualitative methods was appropriate to understand the experience of young carers in the context of the stress process model; individual in-depth interviews and a focus group discussion would enable testing of the model from multiple perspectives. A nominal group and interviews with support workers would allow for identification of potential barriers and facilitators. The importance of the researcher's reflexive position was also discussed.

CHAPTER 3: SYSTEMATIC REVIEW: Identifying the evidence base

Introduction

While research on young carers is growing, there are few studies specific to young carers of people with mental illnesses and their needs, and few systematic attempts have been made to develop and test interventions. To complement a concurrent qualitative study on this topic and in order to develop an intervention, a systematic review of the literature was undertaken to identify the best available existing evidence (MRC, 2008). While reviews, both systematic and otherwise, have previously been conducted of interventions for children of parents with mental illnesses (CoPMI) (Beresford et al., 2008, Fraser et al., 2006), only one review, an economic evaluation, could be found of interventions for young carers affected by parental mental health problems and substance abuse (Crossroads Caring for Carers and The Princess Royal Trust for Carers, 2008).

The review conducted by the Social Policy Research Unit for the Social Care Institute for Excellence (SCIE) (Beresford et al., 2008) was mainly focussed on parents with mental health problems so there were limited outcomes for CoPMI. Of note was one study of higher quality which showed a group cognitive restructuring intervention had preventive effects on sub-syndromal (assessed to have medium severity depression) adolescents of depressed parents (Clarke et al., 2001).

A review of intervention studies for children of parents with a mental illness (Fraser et al., 2006) found seven studies that were deemed methodologically strong and four of moderate quality. However, of these studies, only four were relevant to our current research question, the rest being concerned with depressed mothers and their infants. The relevant studies were two intervention studies led by Beardslee published in 1992 and 1997 and two led by Clarke (Clarke et al., 2001, Clarke et al., 2002). Although the review by Fraser *et al* (2006) was the first that could be found in this field, it was not a systematic review.

An economic evaluation of interventions for young carers affected by parental mental illness and substance misuse estimated that “for every pound invested in a young

carers' project the saving to the Exchequer and wider society is £6.72" (Crossroads Caring for Carers and The Princess Royal Trust for Carers, 2008). However, this study faced difficulties in estimating the impact of young carers' interventions through a lack of evidence of effect. Neither the interventions (young carer projects working with young carers whose parents/guardians had mental/physical health problems or substance abuse problems), nor the figures on which the savings calculations were based, were focussed on those with mental illness.

Since the literature on interventions for young carers of people with severe mental illnesses was limited and the distinction between young carers and children or siblings of people with severe mental illnesses uncertain, it was decided to extend the remit of this systematic review to include these groups. Other reviews have found a dearth of studies evaluating interventions for young carers of people with mental health problems (Crossroads Caring for Carers and The Princess Royal Trust for Carers, 2008).

Aim and objectives

The aim was to conduct a systematic review of interventions for children, siblings and young carers (aged up to 18 years) of people with severe mental illnesses (SMI) to determine which of them, if any, were effective at improving current and future outcomes in this population.

The objectives were

(i) to update the SCIE review from 2007, using their strategy (Parker and Beresford, 2007) to search for interventions for children of parents with SMI

(ii) to conduct a search of the same databases from inception using terms for young carers and siblings of people with SMI

(iii) to screen the results of these searches according to the study inclusion and exclusion criteria

(iv) to extract relevant data and to appraise the quality of the included studies, and if there were high quality randomised controlled trials (RCTs), to synthesize the results.

Method

An initial search in Medline, PsycInfo and Embase, helped to assess the evidence available and clarify the study eligibility criteria.

Study eligibility criteria

Population: Children or siblings (aged up to years) of people with SMI. SMI was defined as psychotic, affective, personality and obsessive-compulsive disorders. They may or may not be living with the parent/sibling with SMI. They may or may not see themselves as young carers of the person with SMI.

Interventions: Any intervention that takes place in the community. The intervention must be delivered to the child, or to the child and the parent/sibling. Interventions can be of any kind, e.g., psycho-social, educational, etc.

Comparison: Any type of comparison. The intervention might be compared with treatment as usual (TAU) or against another intervention.

Outcomes: Any type of outcome. At least one of the outcomes measured should be a child-related outcome. Follow-up studies will be included.

Studies: Any type of study will be included. Randomised controlled trials (RCTs) and systematic reviews or meta-analyses are considered most authoritative but all studies will be appraised for quality. Only RCTs of good quality, as defined below, will be included in a meta-analysis.

The exclusion criteria were decided as follows:

(i) Children/young carers/siblings of people with a mental health problem other than severe psychotic or affective or personality or obsessive-compulsive disorders, e.g. postnatal depression, drug or alcohol misuse.

(ii) Any study that is not set in the community (e.g. inpatient)

(iii) Interventions that are aimed only at the affected parent/sibling.

Report eligibility criteria

In addition to these criteria, the following exclusion criteria, as used by the SCIE review (Beresford et al., 2008) were incorporated in our review to maintain consistency.

(i) Case studies

(ii) Opinion pieces

(iii) Not based on structured enquiry, i.e. wholly descriptive

(iv) not English language

(v) PhDs, unless published later

Although the searches using sibling and young carer terms were conducted from inception in each database, this was not compatible with the SCIE search which limited the searches to 1985 onwards. Therefore any studies that had been screened at the title and abstract stage and had taken place before 1985 were excluded. The SCIE review had also excluded books and book chapters from their review and this criterion was incorporated at the full text stage of our review.

Parenting interventions were defined as not direct interventions for children, unless they included a component directed at the children, and were also excluded.

Search strategy

A search was conducted by updating the SCIE search (Beresford et al., 2008) using their systematic map protocol (Parker and Beresford, 2007) from 2007-current. Although the searches were replicated as closely as possible it was not possible to use the search strategies exactly, where databases had changed. Separate searches were added using young carer terms and sibling terms (from inception to current) in the same databases (see Appendix 3.1 and 3.2 for sample search strategies). All searches were limited to humans and English language where permitted by the database. The search results were exported to Endnote.

For each of the three searches, duplicates were removed using Endnote and then all the references were checked manually for further duplicates. Titles and abstracts were then screened according to the eligibility criteria. Articles that were not relevant (e.g. interventions for parents looking after children with mental illnesses) or that met any of the exclusion criteria were excluded. References for which abstracts were missing and where the titles indicated potential relevance were kept for the next stage of screening.

In the next stage of the screening process, the full text was found for all references that had passed the initial screening of titles and abstracts and these were assessed for

eligibility for inclusion according to the criteria specified above. The selection process has been represented in the form of a PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) diagram (Moher et al., 2009) in Figure 3.1.

Reliability of assessment

In order to check the reliability of decisions made to include or exclude the full text articles, a percentage (20%) of the screened results for each of the three searches was independently assessed for eligibility by a second researcher (K.S.) according to the criteria listed above. The references that were assessed as full text articles were numbered within each search strategy and a random integer sequence generator on the internet (www.random.org) was used to generate the reference numbers in a random sequence. The references corresponding to the first 20% of the sequence generated were sent to the second researcher (K.S.).

Both researchers independently assessed the full text references as 'yes' (to be included), 'no' (to be excluded) and 'maybe' (could be included but needs to be discussed). The level of agreement in the decisions made was measured using Cohen's kappa, bearing in mind the Cochrane collaboration's recommendation to consider the reason for disagreement and its impact on the review (Higgins and Green, 2011). Thus the references for which there was disagreement were discussed in order to try to reach consensus. All references assessed as 'maybe' by this researcher were also discussed with the second researcher (K.S.).

Data extraction

A large spreadsheet was created to describe all the elements of each study. The need for independent data extraction was not deemed critical since it was unlikely that there would be enough sufficiently similar studies for a meta-analysis.

Risk of bias

The different components of RCTs considered to be important for internal validity of a trial (Higgins and Green, 2011, Liberati et al., 2009) were examined prior to synthesis and the risk of bias was assessed as 'high', 'low' or 'unclear' for each component within each study included in the review. The risk of bias was assessed using the Cochrane risk of bias assessment tool, despite its complexity and the fact that all means of identifying

bias can be described as arbitrary and have some disadvantages (Higgins and Green, 2011). A percentage (57%) of the RCTs included in the review were independently assessed by a second researcher (K.S.).

In order to assess the risk of bias for all the included studies which were not RCTs, the studies were assessed using a combination of the Cochrane tool (Higgins and Green, 2011) with one that was based on the STROBE (Strengthening the Reporting of Observational studies in Epidemiology) guidelines (Barley et al., 2011). Again the risk of bias was assessed as 'high', 'low' or 'unclear' for each element of the two tools, with a second researcher (M.P.) independently assessing a percentage of the studies (60%).

Finally, any qualitative studies that were included in the review were appraised using the Critical Appraisal Skills Programme tool for qualitative research (Critical Appraisal Skills Programme, 2006). A second researcher (J.M.) independently assessed one of the qualitative studies, since there were very few.

The independent appraisals helped to reduce subjectivity in assessing bias and any differences in judgement were discussed to arrive at a consensus. The studies assessed by only one person were reviewed to ensure consistency in judgement after discussion.

Narrative synthesis

The narrative synthesis includes the following elements: a theoretical understanding of the intervention, synthesis of the findings according to outcome type and synthesis of the findings according to intervention type.

Results

Searching and screening

The literature search updating the SCIE review was conducted from the beginning of August to the beginning of September 2010. Of the databases searched in the SCIE review, the National Research Register stopped archiving documents in 2007; Social Work Abstracts, ChildData and Communitywise databases could not be accessed through King's College London. The researcher was informed by a Senior Information Specialist at SCIE that the software supporting CareData was changed in 2005 and identical searches could not be re-run, and that the material on SIGLE (System for

Information on Grey Literature in Europe) has not been updated since 2005. Thus the number of databases searched was reduced to 11 (see Appendix 3.3 for list of databases searched and number of references found). From a total of 7220 references found, 1701 duplicate references were removed, leaving 5519 references to be screened (see Fig 3.1 for a flowchart of the systematic selection process).

For the searches using terms for young carers and siblings, 13 databases were searched, including Social Care Online and the National Research Register Archive. From a total of 387 references found for the young carer search, 214 were screened by their titles and abstracts after removing 173 duplicate references. The search using sibling terms produced 1844 references, from which 300 duplicate references were removed, leaving 1544 references.

The young carer search in the National Research Register Archive produced no results, but the sibling search produced 533 results. These could not be exported easily to Endnote, so they were screened online according to titles and abstracts. None were found to be relevant.

A final update using the SCIE search strategy was conducted in September 2011. 2294 references were found, from which 348 duplicates were removed and 1946 references were screened by title and abstract.

Screening of full text

From the initial screening of titles and abstracts, 63 (SCIE search) + 17 (young carer search) + 28 (sibling search) full text articles were retrieved and assessed. The number of references excluded and the reasons for exclusion can be seen in Figure 3.1. Where the reason for exclusion is given as population, this indicates that the population in the study did not meet the population criteria for this review, e.g. it included parents with substance abuse or postnatal depression. 19 full text articles were retrieved and screened for the final update.

This resulted in 16 full text documents from 14 studies, 7 of which were RCTs, 5 were non-randomised studies (NRS) and 2 were qualitative studies.

Fig 3.1. A PRISMA flowchart of the systematic selection process

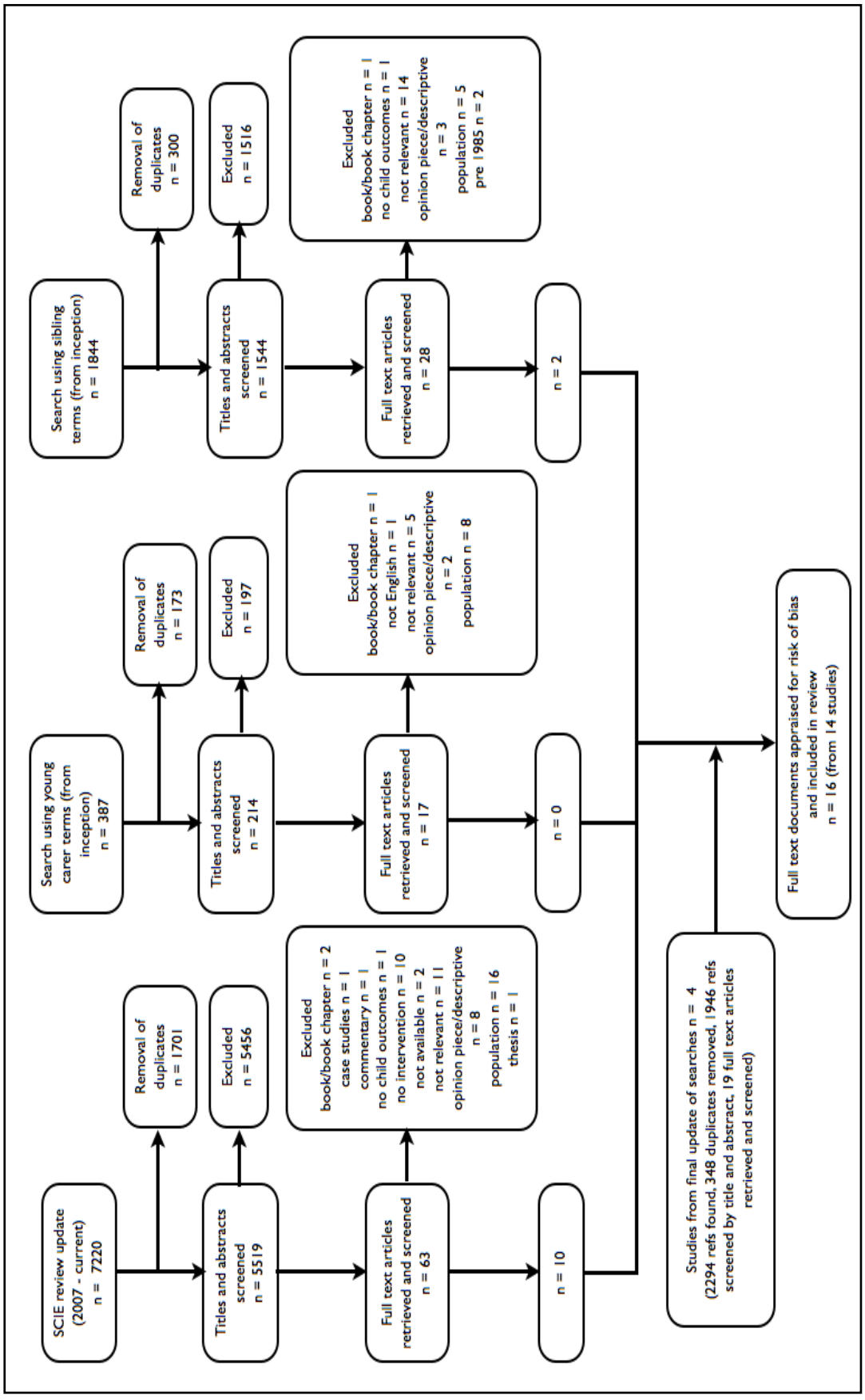


Table 3.1: Decision to include or exclude 20% of full-text articles by two reviewers

		Review author 2			
		Include	Exclude	Unsure	Total
Review author 1	Include	0	0	0	0
	Exclude	4	12	1	17
	Unsure	2	2	1	5
	Total	6	14	2	22

Reliability of assessment

20% of the full text articles from each search were independently assessed. The comparison of decisions made for these 22 references can be seen in Table 3.1. Full text articles (n=9) for which there was difference of opinion between the two researchers were discussed in order to come to a consensus. Cohen's kappa was calculated to be 0.16 using the formula in the Cochrane handbook (Higgins and Green, 2011). This value, according to the Cochrane group, is low. However, as the group has pointed out, it is important to look at the reasons for the kappa value. As can be seen from Table 3.1, there was more agreement on the articles to be excluded than those to be included. Since all the full text articles judged as unsure by A.L. were discussed with K.S. in addition to those with differing judgement, it is unlikely that any false negatives occurred i.e. any studies were excluded which should not have been.

Data extraction

Each of the studies selected for review can be seen in Tables 3.2 and 3.3. From Table 3.2 it can be seen that most of the studies were conducted in the U.S.A. and most of them are for families with a parent with depressive disorder. Only one RCT for siblings was found. The age group of the children included ranges from 7-17 years. It is also worth noting that most of the interventions were either based on the family intervention by Beardslee *et al* (1992) or the cognitive restructuring intervention of Clarke *et al* (2001) or a combination of the two. Some of them had small samples which makes their power to show effects questionable.

Table 3.2: Randomised controlled trials selected for review

Reference	Country	Intervention	Who for	Mental health problem	Study numbers
Barrett *et al*, 2004	Australia	Individual or Group Cognitive Behavioural Family-based Therapy combining cognitive therapy with family psychoeducation	Children (7-17 yrs), their parents and siblings (7-17 yrs)	DSM-IV primary diagnosis of OCD	Individual CBFT: 24 subjects, 13 siblings Group CBFT: 29 subjects, 10 siblings Waitlist: 24 subjects, 9 siblings (block randomization)
Beach *et al*, 2008	U.S.A.	Strong African-American Families programme: family skills training - regulated-communicative parenting techniques, youth intrapersonal competencies, family communication & activities	Fifth grade rural African-American youth and their primary caregivers	Primary caregivers scored ≥ 16 on CESD	167 families. subset (25%) of original sample Intervention: 98 families Control (leaflets by post): 69 families (cluster randomization by county)
Beardslee *et al*, 2007	U.S.A.	Clinician facilitated family communication & psychoeducation intervention	Families with at least 1 child (8-15 yrs) and 1 parent	Parent with an episode of mood disorder in the 18 mths before contact	105 families (21 pilot + 84 after)
Compas *et al*, 2009, 2010, 2011	U.S.A.	Combination of Beardslee family intervention (1992) and Clarke *et al* cognitive skills training (2001)	Parents and children (9-15 yrs)	Parent with current or past MDD	111 parents and 155 children Family intervention: 56 families Written information: 55 families
Garber *et al*, 2009	U.S.A.	Clarke *et al* (2001) group cognitive behavioural prevention programme	Adolescents (13-17 yrs)	Parent or caretaker with an MDD episode during the past 3 yrs or ≥3 MDD episodes or ≥3 cumulative years in an MDD or dysthymic episode within the youth's lifetime	316 adolescents CB prevention programme: 159 adolescents usual care: 157 adolescents
Ginsburg, 2009	U.S.A.	Coping and Promoting Strengths Program: increasing strengths & resilience, reducing risk factors, increasing communication & understanding; combination of CBT and Beardslee's family intervention	Children (7-12 yrs) and their parents	Parents with current or lifetime DSM-IV primary diagnosis of anxiety disorder	40 families CAPS: 20 families Waiting list: 20 families
Solantaus *et al*, 2010	Finland	Beardslee Family Talk Intervention compared with psycho-educational intervention with parents (Let's Talk about children)	Parents and children (8-16 yrs)	Patients diagnosed and currently treated for any ICD-10 mood disorder	FTI: 53 families LT: 53 families (block randomization)

Table 3.3: Non-randomised studies selected for review

Ref	Country	Study type	Intervention	Who for	Mental health problem	Study numbers
Clark & Smith, 2009	Australia	Survey of staff (agency staff, project workers, Interagency & Advisory Committee members) in agencies participating in protocol implementation	The "Protocol to Enhance Interagency Responses for Children of Parents with a Mental Illness" provides guidance for interagency collaboration.	Children of parents with a mental illness	Not stated	Data were collected from staff from 6 agencies participating in protocol implementation. 173 staff at T1 and 130 staff at T2
D'Angelo *et al*, 2009	U.S.A.	Cultural adaption of Beardslee family intervention and evaluation of its safety and feasibility	Beardslee Family Talk intervention adapted for use with Latino families	Self-defined Latino parents and children (7-17 yrs)	Current or previous serious depressive disorder (DSM-IV)	Parents n=9, children n=8 (all children from each family participated in intervention, only one child was assessed)
Goodyear *et al*, 2009	Australia	Evaluation of pilot intervention (pre and post study), no control, two versions of intervention	Children And Mentally ill ParentS (CHAMPS): strengths-based peer support pilot intervention	Children of parents with a mental illness (aimed at 8-12 yrs, included 6-13 yrs)	Parental mental illness included anxiety, depression, bipolar disorder, BPD, PTSD, schizo-affective disorder and schizophrenia	69 children who completed post-intervention assessments (of 129 who attended intervention programmes) 31 attended school holiday programmes, 38 attended after school programmes, 34 attended both
Riebschleger *et al*, 2009	U.S.A.	Evaluation of pilot intervention (pre and post study), no control	Youth Education and Support (YES) pilot group intervention	Children of parents with a mental illness (11-16 yrs)	Parental mental illness included bipolar, personality, schizo-affective, dysthymic and psychotic disorders, anxiety and depression	17 children
Reupert & Maybery, 2009	Australia	Qualitative study using interviews with CoPMI programme facilitators	Multiple intervention strategies including discussion groups, peer interaction, psycho-education, activites, exercises to enhance coping and resilience	Children of a parent with a mental illness (5-18 yrs)	No data collected, suggested to include bipolar disorder, depression, dual diagnosis, schizophrenia & anxiety	18 facilitators running 26 programmes
Reupert & Maybery, 2010	Australia	Qualitative study using interviews with CoPMI programme facilitators	Educating children about parental mental illness (provided extensively by 12 facilitators and to a minor extent by 3 facilitators)	Children with at least one parent with a mental illness (mostly 8-12 yrs)	No data collected, suggested to include bipolar disorder, depression, dual diagnosis, schizophrenia & anxiety	18 facilitators running 26 programmes
Valdez *et al*, 2011	U.S.A.	Evaluation of pilot intervention (pre and post study), no control	Keeping Families Strong (KFS): family-focussed multi-family group intervention incorporating psycho-education and cognitive behavioural strategies	Mothers, their partners and children (9-16 yrs)	Mothers currently in treatment for depression	10 mothers and 16 children

Similarly the non-randomised studies selected for inclusion in the review were all also from the U.S.A. or Australia. Most of them were pilot studies of interventions without a control condition using pre and post evaluations. Three interviewed or surveyed staff about the impact of an intervention for children of parents with mental illnesses (CoPMI) and two of these were qualitative studies. The studies included a wide age range and different kinds of parental mental illnesses. The sample sizes were small for some of the studies but this is understandable given that they were pilots.

Risk of bias

The combined assessment of risk of bias for RCTs is given in Table 3.4. 4 out of 7 RCTs were independently appraised and any differences were resolved by discussion. The consensual assessment for those studies is shown. The main difficulty faced by these studies, and by definition they could only be single blind at best, was the adequacy of these procedures. As with most RCTs of complex psychological interventions, there was the issue of how effectively the outcome evaluators had been blinded to the allocated condition. Most studies had either not been clear about whether the outcome evaluators were independent or actually blind to condition, or whether this was checked after the trial. Some studies had also not clearly stated their method of random sequence generation or allocation concealment, making it difficult to assess whether randomisation was adequate.

Table 3.4: Assessment of risk of bias for 7 randomised controlled trials

Criteria	High risk of bias	Low risk of bias	Unclear risk of bias
Random sequence generation (selection bias)	1	4	2
Allocation concealment (selection bias)		4	3
Blinding of participants and personnel (performance bias)	5	2	
Blinding of outcome assessment (detection bias)	3	1	3
Incomplete outcome data assessed (attrition bias) Short-term outcomes (2-6 weeks)	1	5	1
Incomplete outcome data assessed (attrition bias) Longer-term outcomes (>6 weeks)	1	5	1
Selective reporting (reporting bias)			7
Other bias*		2	

4/7 were independently appraised and any disagreements were resolved by discussion
* other bias assessed only if existing

The assessment of risk of bias for the NRS can be seen in Table 3.5. The main issue with the pilot studies is the fact that without a control condition it is difficult to know whether the result was due to the intervention or to the fact that participants were receiving attention. It was frequently difficult to assess how representative the sample selected was, given the limited information provided in the articles, and the small sample sizes made the accuracy of results uncertain. Thus the NRS provide little evidence of effect given the difficulty in establishing causality of intervention effect without a control.

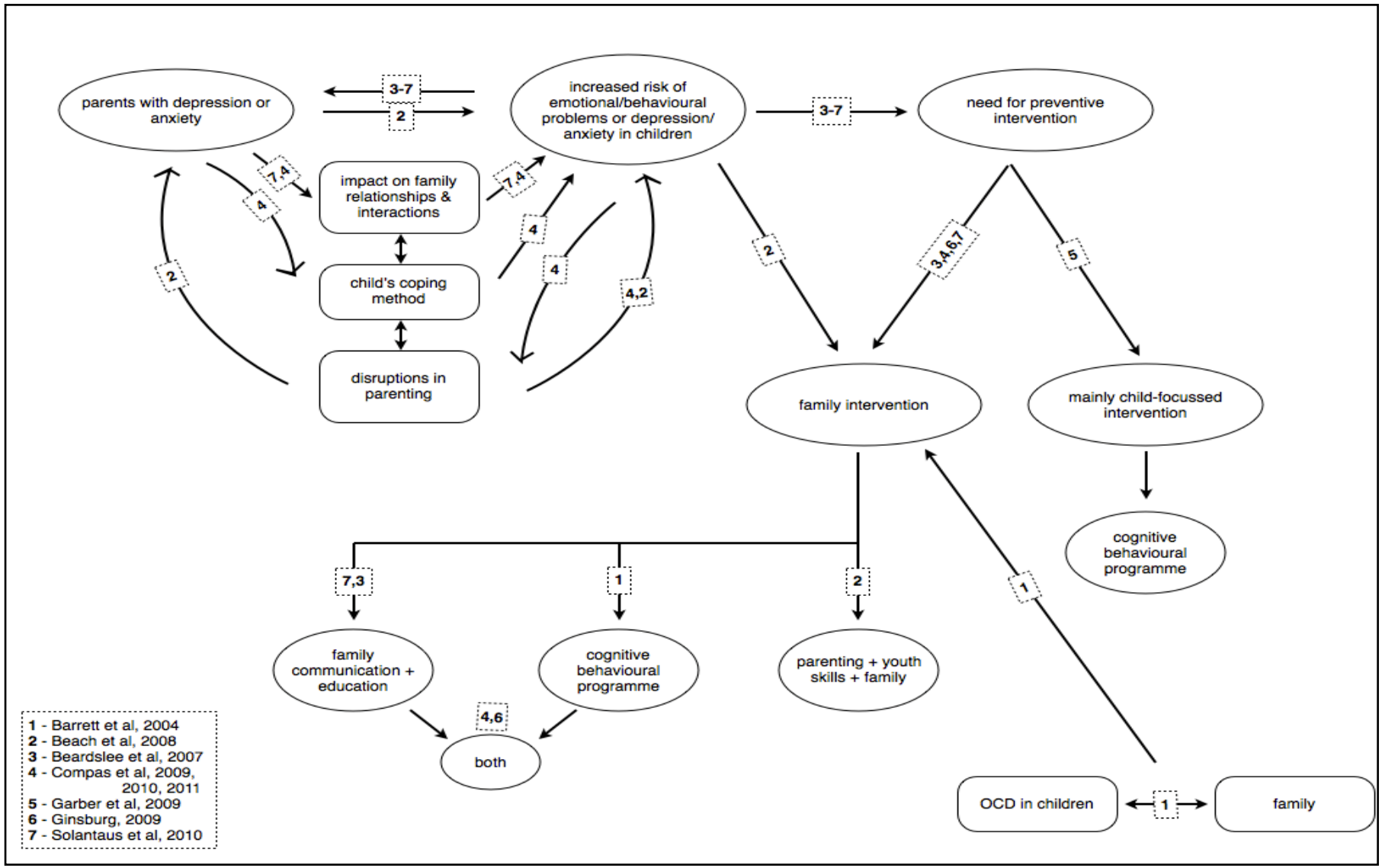
Although the qualitative studies (Reupert and Maybery, 2009, Reupert and Maybery, 2010) explored the interventions offered by CoPMI programmes in Australia, the interventions varied largely in content and delivery. Using the CASP tool for qualitative studies with an independent assessment of one of the studies, the quality was felt to be reasonable for the two studies with a score of 8 for Reupert & Maybery (2009) and scores of 6.5 and 7 (from the two assessors) for the 2010 paper. However, there was no data collected on the exact nature of the parental mental health problems.

Table 3.5: Assessment of risk of bias for 5 non-randomised studies

Criteria	High risk of bias	Low risk of bias	Unclear risk of bias	Not applicable
Incomplete outcome data assessed (attrition bias) Short-term outcomes (2-6 weeks)	1	2	1	1
Incomplete outcome data assessed (attrition bias) Longer-term outcomes (>6 weeks)				5
Selective reporting (reporting bias)			4	1
Other bias*	1	1	1	
Was the selection of participants appropriate?	3	2		
Was the measure of variables appropriate?	2	2	1	
Was there appropriate control of bias?	2	1	2	
Was the use of statistics appropriate?	3	1	1	
Was the study free from conflict of interest?		1	4	

3/5 were independently appraised and any disagreements were resolved by discussion
* other bias assessed only if existing

Figure 3.2: Conceptual model of theoretical background of randomised controlled trials



Narrative synthesis

Theory

Each study was examined for its theoretical framework in order to understand the anticipated contributing factors and potential mechanisms for each intervention. These have been combined in a single figure (see Figure 3.2), in order to be able to compare theoretical frameworks across studies, as well as to compare it to the stress process model posited in Chapter 1. From this it can be seen that most of the RCTs were based on the theory that children of depressed (or anxious) parents are at higher risk for emotional and behavioural problems and for depressive or anxiety disorders themselves. Thus, most of the studies were founded on the need for preventive interventions.

Different moderators and mediators were hypothesized for the relationship between parental depression/anxiety and risk to children, including the impact on family relationships and interactions, children's method of coping (use of secondary control coping methods) and the disruptions to parenting. The interventions were aimed at returning what would ideally be a positive relationship (e.g. support from a parent), which is now more negative due to the illness, back to a positive one. The Barrett *et al* (2004) study was an exception since the relationship on which it was based, was a circular one between a child with OCD and his/her family.

As has been described, the interventions were mostly family interventions and were either based on the Family Talk Intervention by Beardslee *et al* (1992) or the cognitive restructuring techniques of Clarke *et al* (2001) or a combination of the two. Beach *et al* (2008) had a different aim since it was mainly focussed on strengthening low-income African-American families. Some of the theoretical relationships put forward by that study (e.g. between parental depression and parenting) could be understood in terms of our main model. Garber *et al* (2009) was the only child-focused intervention.

The NRS followed similar lines, for example, based on Beardslee's family psychoeducation intervention model (D'Angelo et al., 2009). Riebschleger (Riebschleger et al., 2009) used a stress coping model to develop a psychoeducation intervention, theorising that improving coping in youth with a parent with psychiatric illness, would reduce risk of developing psychiatric outcomes and increase resiliency. Goodyear *et al.* (2009) similarly looked to use a strengths-based peer-support

intervention to increase resilience and reduce risk in CoPMI. Family stress theory laid the basis for another pilot study which focused on families as the 'agent of change' and looked to improve outcomes through family support, positive parenting, family activities, and communication (Valdez et al., 2011).

Synthesis according to outcome type

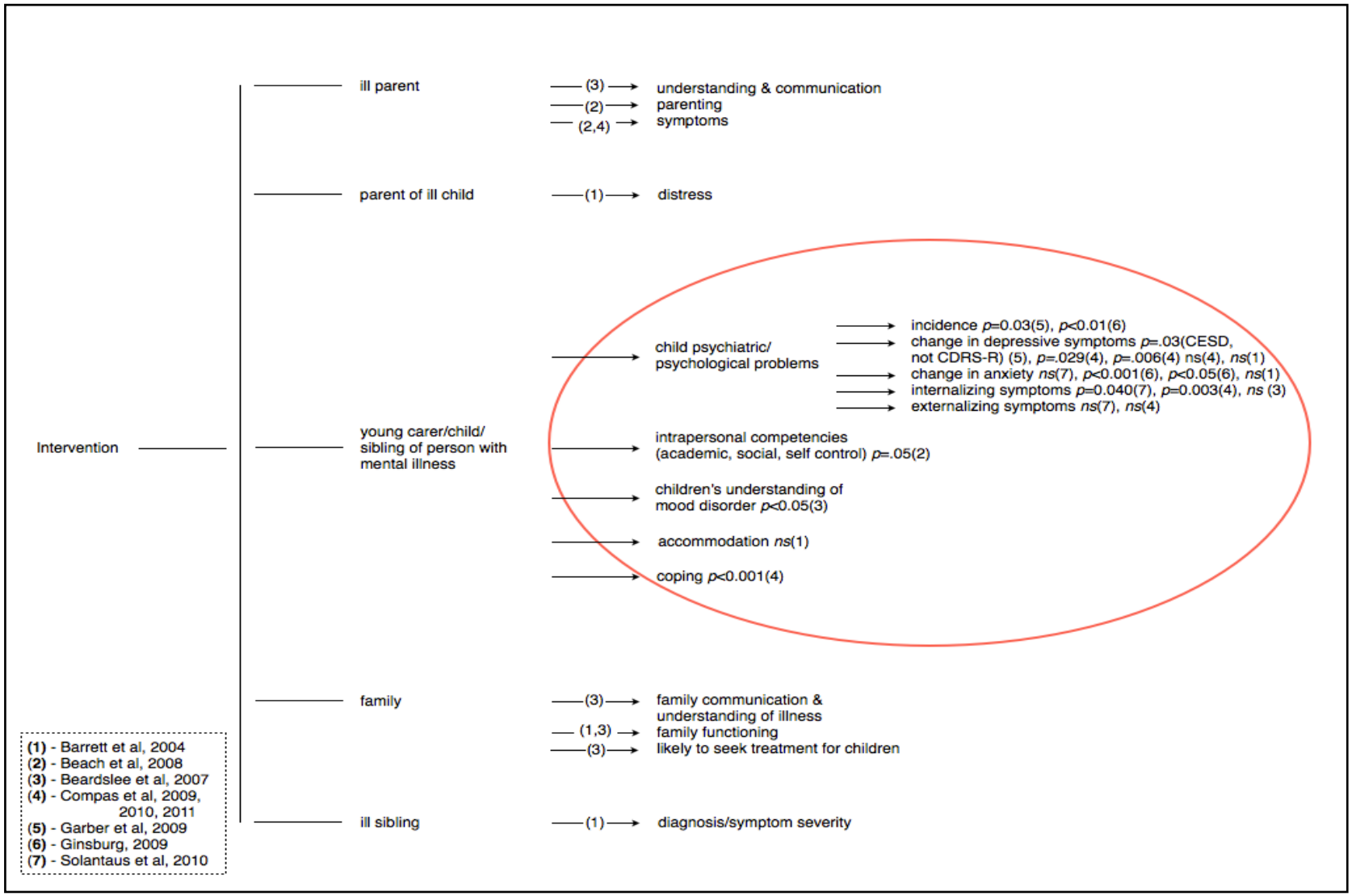
The outcomes at which these interventions were directed can be seen in Figure 3.3. The number for each study is given in the key. Although most studies included non-child related outcomes, the focus of this review is on child outcomes. The focus is also on primary outcomes which are the differences between intervention groups within each study. In order to be informative, non-significant (*ns*) relationships have also been included. However, since different studies used different measures, it was difficult to compare effects across studies.

Most of the child outcomes under study were psychiatric or psychological problems. Both Garber *et al* (2009) and Ginsburg (2009) found that their interventions had a significant impact on incident depression (p=0.03) and incident anxiety (p<0.01) respectively. However, Garber *et al* (2009) also found that current parental depression at baseline was a significant moderator i.e. there was a difference between groups if a parent was not depressed at baseline (p<0.001) but there was no significant difference in youth incident depression between groups when parents had a current depressive episode at baseline (p=0.26).

While Garber *et al* (2009) found a significant difference (p=0.03) between the interventions over time on the Centre for Epidemiological Studies Depression scale (CES-D), the same was not found on the Children's Depression Rating Scale - Revised (CDRS-R). Barrett *et al* (2004) did not find a significant difference between groups for sibling depression. Compas *et al* (2009) found a significant effect on CESD scores at 12 month follow-up (p=0.029) and for anxiety/depression symptoms on the Youth Self Report (YSR) at 2, 6 and 12 months (p=0.006). However, no significant effect was found on the Child Behaviour Check List (CBCL) scores or for depressive episodes since baseline (p=0.070).

Ginsburg (2009) also found significant effects for the intervention on reduction in anxiety scores (p<.001; p<.05) but this was not reflected in the child-reported measure.

Fig 3.3 Outcomes of interest for each intervention (n=7 RCTs) and effects on child outcomes



Barrett *et al* (2004) found no significant difference for sibling anxiety, and although there was a significant improvement in children's anxiety over time in both intervention groups, the difference between groups over time was not significant in the Solantaus *et al* (2010) study.

The intervention administered by Solantaus *et al* (2010) had a significant effect on emotional symptoms in comparison with the control group (p=0.040). Compas *et al* (2009) found an effect on the YSR internalizing symptom scores (p=0.003), but not on the CBCL scores. Baseline scores predicted internalizing symptoms later in Beardslee *et al*'s study (2007) resulting in no main effect for the intervention group.

Solantaus *et al* (2010) found no significant difference between intervention groups over time on hyperactivity, conduct problems, peer problems or prosocial behaviour, and Compas *et al* (2010) found no significant differences between groups on either the YSR or CBCL externalizing scores.

Other outcomes of interest for which intervention effects were sought were youth intrapersonal competencies (p=0.05; Beach et al., 2008), children's understanding of mood disorder (p<0.05; Beardslee et al., 2007), sibling accommodation (ns; Barrett et al., 2004) and coping (p<0.001; Compas et al., 2010).

In addition to these child outcomes from RCTs, some child outcomes from the NRS were indicated, bearing in mind the methodological limitations of these study types discussed previously. The qualitative response from staff surveyed suggested that collaborative inter-agency practice in mental health services in Australia was of benefit to CoPMI, but little detail was provided for the same (Clark and Smith, 2009). One small pilot study adapting the Beardslee psychoeducation intervention for Latino families found no change in the functioning and behaviour of children of mothers with depressive disorder. Youth participating in another pyschoeducation programme showed improved knowledge of psychiatric illness and rehabilitation but no improvement in coping, from pre to post intervention. The Goodyear *et al* (2009) non-randomised study compared two methods of delivery of the same intervention and showed a significant difference between groups over time on problem-focused coping but there were issues with bias, particularly with incomplete outcome data. A family-focused intervention

showed small improvements in children's adjustment, coping, and evaluation of their parents, but worsening of maladjustment in school (Valdez et al., 2011).

Covariates, mediators and moderators

Some studies controlled for some covariates at the point of sample selection, e.g. some specific illnesses, other life stressors or family crises. Some controlled for covariates in the analyses, like parent depression at baseline (Solantaus et al., 2010) especially current depression (Garber et al., 2009; significant moderator of intervention on incident depression), baseline covariates (Compas et al., 2009, Garber et al., 2009), completion status (Beardslee et al., 2007; $p<0.05$ with children's understanding), changes in parent behaviour and attitudes at previous stages of the intervention (Beardslee et al., 2007; $p<0.001$ with children's understanding), adolescent depressive symptoms and history (Garber et al., 2009) and correct guessing by evaluator (Garber et al., 2009; effect of intervention no longer significant). Solantaus *et al.* (2010) showed that an important and potentially confounding variable can be the relationship between improvement in parent condition/symptoms and improvement in child outcomes. Thus the effectiveness of family interventions might be crucially dependent on improvement of illness symptoms in the parent/sibling (Beach et al., 2008).

Positive parenting and adolescent use of secondary control coping were shown to be mediators of the impact of the intervention on adolescent internalizing and externalizing symptoms (Compas et al., 2010) and change in parental behaviour and attitude at the previous assessment point predicted child understanding ($p<0.001$) and made the impact of the intervention insignificant (Beardslee et al., 2007). Although the Strong African-American Families Programme had an effect on youth intrapersonal competencies ($p=0.05$*),* their competencies in turn did not have a significant effect on parent symptoms.

Synthesis according to intervention type

Of the studies that showed significant between-group results, those by Ginsburg (2009) and Compas *et al* (2009) had both used a combination of a cognitive behavioural and a family psychoeducational intervention and showed a significant impact on incident anxiety and coping respectively for the intervention group. The risk of bias for both was assessed as low, except for blinding of outcome assessment which was unclear.

Secondary control coping, however, was studied as a mediator by Compas *et al* (2010) and the effect on the main outcomes varied across measures and over time points (Compas et al., 2009). The intervention trialled by Barrett *et al* (2004), which used a similar combination of interventions, did not have a significant effect between groups on sibling accommodation, but the number of siblings was small and the study might not have been adequately powered for this variable. The risk of bias for this study was mixed, being high for randomization and low for incomplete outcome data.

Garber and colleagues (2009) showed a significant difference between groups for impact on incident depression using a group cognitive behavioural intervention, but this was no longer significant after controlling for correct guessing of group assignment by evaluators. Except for blinding, their risk of bias was assessed as low.

Similarly the family psychoeducation programme by Beardslee *et al* (2007) showed a significant difference for impact on children's understanding, but this was moderated by change in parent behaviour and attitudes at previous time points and was significantly associated with completion status. There were also concerns about risk of bias for the Beardslee *et al* (2007) study since the effectiveness of randomization was unclear and the risk of bias from blinding procedures and incomplete outcome data was high. In the case of the intervention tested by Solantaus *et al* (2010) which showed non-significant results for all outcomes except emotional symptoms, there was no mention of a power calculation, so it is unclear whether the sample size was adequate, especially given the number of variables tested. The risk of bias for this study was mostly low, except for allocation concealment and blinding of outcome data which were unclear.

Finally there was an intervention effect on youth intrapersonal competencies with a family skills training programme but this was exactly significant ($p=0.05$) (Beach et al., 2008). Again, the risk of bias was mostly low except for random sequence generation which was unclear.

Although the two qualitative papers (Reupert and Maybery, 2009, Reupert and Maybery, 2010) were based on the same study, the interventions they covered were different, with the 2010 paper focussing on educational interventions. These studies were helpful in showing that many informal interventions are not theory or needs based,

rarely evaluated properly and could incorporate CoPMI input, but they provided no evidence of effect of any particular intervention.

Interventions from previous reviews

The four relevant studies from the Fraser *et al* (2006) review were assessed by the SCIE review (Beresford et al., 2008) who identified a single RCT from the numerous publications by Beardslee and colleagues (Beardslee et al., 2003) which was an earlier publication of the study we reviewed. They highlighted, as mentioned before, the Clarke *et al* (2001) study but the intervention trialled in the other Clarke *et al* (2002) paper was not found to be effective. Their publications showed a significant preventive effect for an intervention using cognitive restructuring techniques in adolescents with medium severity depression (Clarke et al., 2001) but this was not the case for treatment of currently depressed adolescents (Clarke et al., 2002). There was also no mention of potential covariates considered apart from additional treatment/services used.

Discussion

The finding of 7 RCTs and 7 NRS after systematically searching the literature, shows that there is still little evidence for the effectiveness of such interventions. There was limited evidence that a combination of cognitive behavioural and family psychoeducational interventions had an impact on anxiety and coping outcomes and, from an earlier study (Clarke et al., 2001), that a cognitive restructuring intervention could have a preventive effect on adolescents with subsyndromal depression. The NRS also showed propagation of similar models but limited evidence.

The main value of the systematic review lies in the further understanding of the theory and factors contributing to the impact of interventions. The interventions tested so far have come from a range of theoretical perspectives, as seen in Figure 3.2. There is a need for more innovative evidence-based needs-based interventions for this vulnerable population, with an emphasis on theoretically developed treatments as well as studies which reach high methodological standards. There is also a need for further development of the interventions shown to have some impact. It is particularly interesting that a combination of the two most popular interventions has been shown to have some impact. The active components of the intervention and the relationship between different outcomes need to be further understood. Moreover, the evidence so

far has been limited to children of those with depression and anxiety. There have been no quality RCTs found of interventions for children of those with psychotic disorders.

Studies like the one by D'Angelo *et al* (2009) indicate the importance of a range of factors for a family's optimal functioning, especially in the context of ethnic minority families. The planning of pilot trials can be crucial for modelling the effect of a proposed intervention and in assessing the impact of possible confounding variables such as immigration, poverty or cultural background.

Most importantly, it shows that interventions for this population are focused on the risk to children from parental mental illness. Alternative models, such as the stress process model, that consider contributing factors and positive outcomes of the experience of parental mental illness need to be utilised in the development of interventions for this population. Furthermore, while these are needs-based interventions (as seen in Chapter 1), they also highlight the importance of theory-based interventions that address the variations in family circumstances. Finally, there is a crucial need for supportive interventions for siblings of those with mental illnesses, and for both children and siblings of people with psychotic disorders.

Furthermore, the appraisal of risk of bias raised issues with some of the studies; there were few high quality studies. However, there are always issues with ensuring adequate methods for blinding evaluators in complex interventions, as this depends on resources as well as methodological sophistication. There are also ethical issues of not offering interventions in treatment as usual or control conditions, but until a treatment has been shown to be efficacious it is not unethical to withhold it, so this criticism does not apply to these studies.

Methodological difficulties

The difficulties in attempting to systematically review complex interventions have been discussed in detail (Shepperd et al., 2009) and this review faced similar issues. This review attempted to manage this by searching the literature broadly without specifying intervention terms, and by using a narrative synthesis. By considering the underlying theory and related factors within each study reviewed, it also attempted to increase the utility of the results.

An additional criterion in the initial search was an ICD-10 (International Classification of Diseases - 10) diagnosis of the parent/sibling. This was deemed too narrow, and studies were not screened according to this criterion. However, these issues of the different criteria used to assess participant eligibility in the included studies as well as the variety of measures used to assess outcomes remain, making comparison across studies difficult.

It is recommended that systematic reviews should assess the quality or risk of bias of the studies included (Liberati et al., 2009, Higgins and Green, 2011). While the SCIE review used a combination of the Jadad checklist (Jadad and Enkin, 2007) and Cochrane Effective Practice and Organisation of Care Group (EPOC) checklist (EPOC, 2002) for summary scores of quality assessment (Beresford et al., 2008), more recent guidelines for the conduct of systematic reviews (Liberati et al., 2009, Higgins and Green, 2011) have argued against the use of summary scores, since this can be misleading (Juni et al., 2001) and have recommended assessing methodological components instead.

The force of this argument could be seen, for example, in the scoring for the Jadad checklist in which a study can only score either 0 or 2 for description and 'appropriateness' of randomization, which makes the description of randomization unnecessary (Jadad and Enkin, 2007, fig. 4.1), and in the discussion of quality assessment in the SCIE review where the use of two checklists produced conflicting scores on some studies (Beresford et al., 2008). The SCIE review also used the summary scores from the checklists for discussion of quality, but described the components of their quality appraisal elsewhere, which permitted examination of the same.

The Cochrane tool is challenging but complicated. While it is helpful to have to be clear about one's reasons for making judgements, it is still easy for the judgement process to be subjective. Moreover, guidance on best practice in incorporating the assessment of risk of bias into the analysis is still unclear, since weighting effect sizes according to quality, stratifying the analysis and arbitrarily defining a quality threshold all have disadvantages (Higgins and Green, 2011). There is also a lack of consensus on the appropriate tool for assessing risk of bias in non-randomised studies (NRS).

Limitations

While focusing the review on interventions for children/siblings/young carers of people with mental health problems has been helpful in identifying existing interventions for this population, it has not included interventions for parents that might have an effect on the child. Thus, it should be noted that there will also be interventions through the parents (e.g. parenting interventions) that might affect child outcomes.

The level and extent of the SCIE search could not be completely duplicated in this review, e.g. the SCIE review hand-searched journals and contacted authors, which we were unable to do given the smaller size of the research team, so there is a small chance that relevant studies, particularly those which were not published in a journal, might not have been found. However, a large number of databases was searched, including the National Research Register, reducing this possibility.

Another limitation in this study is the low Kappa value found in the agreement between the two researchers for inclusion of studies, although it has been argued that with few studies, this was more likely to mean studies were over-included in the analysis.

More recent evidence

Since the review was conducted, a systematic review of interventions aimed at the quality of life of children of parents with serious mental illness has been published (Bee et al., 2014). Their objectives included assessing the clinical effectiveness, cost effectiveness and acceptability of community-based interventions. Most of the interventions they reviewed were irrelevant for our purposes because they focused on parents. However, even with the interventions they reviewed, it was found that there was little evidence of effect on children's outcomes. No economic evaluations or cost or resource-use studies were found. The authors noted that the level of trial quality was poor overall, children's self-reported outcomes were rarely included, and very few trials took place in the UK. The authors concluded that the evidence base remains mostly focused on interventions for severely depressed mothers with infant children and that there is a need for systematically developed interventions for children of parents with serious mental illness.

Conclusion

Interventions for young carers (children and siblings) of people with severe mental illnesses are limited, with few high quality studies focused on those whose parents have affective disorders, and with no studies found of family members with psychosis. The topic requires considerable development, particularly with regards to finding appropriate theories that address the issues pertinent to this population on which to base interventions.

CHAPTER 4: QUALITATIVE FINDINGS: Developing theory, modelling process and outcomes

This chapter describes the results of the qualitative data analysis. The first part of the chapter describes the factors considered for inclusion in the stress process model and the second part considers the theoretical fit and relationship of the variables within the model. The analysis is based on the stress process model developed by Pearlin and colleagues (Pearlin et al., 1990) and explores the similarities and differences in such a model developed for young carers. The results described below will be discussed in detail in the next chapter.

Sample

In total, 23 participants were recruited: 13 young people took part in individual interviews and a separate focus group was conducted with 10 participants from a single young adult carers project. One participant, Tarun*, who took part in the focus group was also recruited for an in-depth interview to explore his perspective further, resulting in a total of 14 interviews.

The demographics of the participants who were interviewed are provided in Table 4.1. The 14 interviewed participants, 9 of whom were female and 5 male, ranged in ages from 17 to 25 years old. They included participants from minority ethnic groups, from London and other parts of England (both urban and rural areas), and living both with and away from their families. Participants had mostly cared for siblings or mothers with severe mental illnesses, but the sample included one young adult who was looking after a father with schizophrenia. Finally, while eight of the participants had received support from a young carer or carer project, the sample included participants who had not received such support. Thus the sample was a small but heterogenous sample that included different perspectives from a range of backgrounds.

The 10 participants who took part in the focus group were 6 males and 4 females, with an age range of 17-24 years (see Table 4.2). Most participants were caring for a parent and continued to live with them. Most participants also had other family members living with them. All but one stated that the person they looked after had been diagnosed with

Table 4.1: Characteristics of interviewed participants

Participant ID No	Name (not real)	Age (at interview)	Male/ Female	Black or Minority Ethnic Origin	Location while caring	Currently at	Caring for	Illness (as reported by participant)	In contact with young carers project?
YCP01	**Mandy**	23	F	No	South West England	University (away from family)	Brother	Schizophrenia	No
YCP02	**Irene**	22	F	No	Home Counties	Home (end of work placement year)	Mother	Manic depressive	Yes (Carers)
YCP03	**Simon**	23	M	No	London	Home (distance learning, not in employment)	Brother	anxiety, depression and non-schizoid psychosis	Yes
YCP04	**Rajini**	20	F	South Asian	London	University (commuting from home)	Mother	Depression	Yes
YCP05	**Naima**	23	F	African	London	Working part-time (not living at home)	Sister	Schizophrenia	Yes
YCP10	**Tarun**	24	M	South Asian	East of England	Home (working full time)	Mother and Sister	Mother - Depression due to bereavement Sister - Borderline personality disorder, attachment disorder, previous bipolar, who took her own life	Yes
YCP16	**Huy**	17	M	South-East Asian	London	College (living with aunt)	Mother	OCD	Yes
YCP17	**Pauline**	25	F	No	London	Living with partner (on maternity leave)	Mother	Severe psychotic mood disorder	Yes
YCP18	**Beatrice**	24	F	No	East of England	Work (away from family)	Brother	Schizophrenia	No
YCP19	**Arthur**	22	M	No	West Midlands	University (away from family)	Father and Mother	Father - physical Mother - Depression and mild schizophrenia	Yes
YCP20	**Clover**	23	F	No	Information not available	University (away from family)	Mother	Depression	No
YCP21	**Enid**	24	F	No	North of England	University (away from family)	Mother	Bipolar	No
YCP22	**Abdul**	19	M	South Asian	Information not available	University (living at home)	Brother	Multiple diagnoses including ADHD and schizophrenia	No
YCP23	**Antonia**	23	F	Mixed ethnicity (South American & English)	South-West England	University (away from family)	Father	Schizophrenia	No

Table 4.2: Characteristics of participants who took part in the focus group

Participant ID No	Age (at focus group)	Male/ Female	Who do you care for?	Do you live with the person you care for?	If yes, who else lives with you? If no, with whom do you live?	Has the person you care for ever been diagnosed with a mental illness?	If yes, what was the diagnosis?	Are you currently at	How many hours per week do you think you spend caring?
YCP06	17	M	mother	Yes	Father, brother	Yes	depression, mental health issues	Other (College)	how ever many needed
YCP07	17	F	mother, father	Yes	Mum, Dad, Brother	Yes	severe depression	Other (College)	62ish
YCP08	17	M	father	Yes	mum, 1 sister, 5 brothers, dad	Yes	schizophrenia	Other (YMCA training)	62ish
YCP09	17	M	mother, father	No	on my own	Yes	severe depression	Other (College)	62ish hours
YCP10 (Tarun)	24	M	mother, sister (until the year before)	Yes		Yes	mother - depression (due to bereavement), sister - borderline personality disorder, attachment disorder, previous bipolar	Work	varies 1-20 hours per week
YCP11	19	M	mother	Yes	my dad	Yes	high depression	Work	When my dad needs it
YCP12	17	F	father	Yes	my mum, younger brother, older sister	Yes	manic depression	Other (College)	weekends and sometimes after college
YCP13	17	F	father	No	(moved away)	No		Work (Volunteering)	N/A
YCP14	24	M	mother	Yes	no just my mum	Yes	depression, mood swings, panic attacks, memory loss, house bound	Work	50
YCP15 (Simone)	21	F	someone else (partner/girlfriend)	Yes	just myself + partner + kitten	Yes	borderline personality disorder + bipolar	University	full-time less 2 x half days a week during term time

a mental illness. The exception was YCP13 who was unclear about her father's illness. Most participants were in education or employment.

In order to understand the context for the quotations from transcripts used as examples of the identified themes, a table with a brief summary of each participant's story has been provided below in Table 4.3.

Table 4.3: Narrative summaries of interviewed participants

Mandy* is 23 years old and is at University. She lives away from home but visits her family regularly. Her older brother was diagnosed with schizophrenia§ when Mandy was 17, but it was even earlier that he first began to show signs of a mental illness and became very antisocial. He is much better now and Mandy attributes this to the family's care. She looks after him by helping to prevent alcohol and substance misuse and by acting as a confidante. The interview with Mandy was the first one and initiated the researcher's understanding of a young carer's experience from their perspective. The need for information was particularly highlighted in this interview.
Irene is 22 years old and also at University. She previously lived with her mother, and her father and brother live elsewhere. Her mother has been manic depressive all her adult life. Irene describes her mother as a stable parental figure when she was well, but then she became ill very quickly and took a potentially lethal overdose. As the family member who was on the spot as her mother was in and out of hospital, Irene dealt with emergency situations, tried to obtain information about her mother's progress, acted as the link between hospital staff and other family members, and voiced concerns when she felt that her mother was not well. She organised her mother, encouraging her to continue to function and helping her to do things. Her caring role and the level of care she had to provide varied as the illness changed. Irene has had help from the local Carers service. This interview was helpful in understanding the difference between a young carer who has family support and one who has sole responsibility.
Simon is 23 years old and looks after his younger brother who has been diagnosed with anxiety, depression and non-schizoid psychosis. Simon has looked after both his younger brothers since he was young because both his parents are working and he sees himself as the primary carer for the brother who developed mental health problems when he was 15. His caring role included keeping a constant watch over his brother to prevent him from harming himself or other people and looking after things like his medication and meals. As he grew older, he also took on more housekeeping responsibilities like doing the laundry and cooking. Simon feels that his caring role enables his parents to continue working and providing for the family. He was put in touch with the local Young Carers service which helped him with one-to-one support, trips and time away from his caring responsibilities. Interviewing Simon raised questions about who the primary carer was in a family and how he/she was identified.

Rajini is 20 years old and lives with her mother, while attending University. Rajini is the sole carer for her mother, who developed depression when Rajini was 10 or 11. Her mother is from a South Asian family and because of cultural influences and because of her mother's difficulties with socializing, Rajini feels that her own ability to socialize with her peers has been impacted. Rajini provides a lot of emotional support for her mother and sees herself as the purpose of her mother's life. She also helps with the housework. She was put in touch with a young carers service when she was 15 or 16 and, of its activities and services, she felt she benefited most from the contact with a supportive adult whom she could talk to. Rajini's interview was the first to explore cultural issues and the impact of a minority ethnic background.
Naima is 23 years old, with a younger brother and an older sister. Her sister began showing symptoms of schizophrenia when Naima was about 11. Naima now lives away from home and works part-time. Her family is of African origin. Her mother is the primary carer for her sister but, before she moved away from home, Naima helped to look after her sister by providing emotional support, e.g. by talking to her or holding her hand when she was feeling down. More recently, she helps by providing respite for her mother on occasion. Naima has been in contact with a young carers service since she was 13, which gave her an outside focus, a place where she could take part in social activities, vent her frustration, and meet other people who were in a similar situation. Her interview provided an example of good practice in mental health services by involving and supporting families.
Tarun is 24 years old, from a South Asian family, and lives with his mother who has both physical conditions and depression. She was diagnosed with depression after Tarun's older sister died from an overdose after years of different mental health problems, including abusing solvents and self harming. Tarun cared for his sister by trying to protect her, by dealing with emergency situations, and by providing advice and emotional support. Tarun looks after his mother when she is feeling depressed by providing emotional support, e.g. by being there, by keeping her company and by keeping her occupied. Tarun and his mother received support through an advocacy worker from a family carers service, and Tarun received limited support from a young adult carers project. Interviewing Tarun was helpful in highlighting the sense of responsibility that might be the common factor that identifies carers.
Huy is 17 years old, of South-East Asian origin, and attends College. His mother, whom he visits once a week, has an obsessive-compulsive disorder (OCD) and was sectioned when Huy was 15. Huy also has OCD and has been seeing a psychiatrist for the last 3 years. Huy found it difficult to identify any caring responsibilities that he had, partly because his mother can manage on her own, and partly because he is not allowed to see her very often for his own mental health. He has been in touch with a young carer project. Huy's interview was unique because he could not identify any caring responsibilities that he had but was still receiving services from a young carer project.
Pauline is 25 years old and lives with her partner. She looks after her mother who developed mental health problems when Pauline was 3. Her mother was diagnosed with severe psychotic mood disorder and also has a physical disability which meant that Pauline did all the housework from the time she was 13 as well as looking after her younger brother. She had to start working when she was 16 to support the family. Even now, she continues to look after her mother and to support her financially. She has had one-on-one support from a young carer project.

Beatrice is 24 years old and in employment. She is the youngest of a family of six children, three of whom are step-siblings. Her eldest brother (of her own siblings) developed schizophrenia when Beatrice was 11 or 12 and was hospitalized, and Beatrice was the only child at home with their parents when he returned from hospital. As Beatrice grew older, it increasingly became her role to look after her brother, for example, by helping to make sure he took his medication. She was also the one who encouraged her parents to let her brother move into supported living and more recently, she has also provided emotional support for him. Beatrice's interview again raised the question of how the primary carer in a family is determined.
Arthur is a 22 year old student, currently living away from home, and has cared for both his parents since he was 6. His father has physical health problems and his mother has a combination of physical and mental illnesses, including depression and mild schizophrenia. He was put in touch with a young carers group when he was 14, which helped him with respite, meeting other young carers and having somebody who could act as an advocate for him with his school. Arthur provided physical care for both parents and emotional care for his mother and even acted as a mediator between his parents when relations were strained. He has had experience in speaking as a young carer at conferences, providing a young carer's perspective to professionals and other people. Arthur's interview provided insight into the difficulties of young carers when they reach a transitional stage on the verge of adulthood. It also widened the researcher's understanding of what schools could do to help young carers.
Clover is 23 years old and a student at University, living away from home. Both her parents had depression: her father when she was 14 (her mother cared for him) and, after he got better, her mother fell ill and has been ill ever since. She helped to care for her mother by making sure she had her meals and medication, helping with the housework and making sure she was all right, including handling the situation when her mother took an overdose.
Enid is a 24 year old student who has cared for her mother with bipolar disorder since her sister left home. They also had help from their extended family. From her experience of looking after her mother, Enid was always very aware of when her mother was not well and would try to get help from mental health services. She also helped by keeping things normal at home when her mother returned from hospital, for example by allowing her mother to look after her. Enid's practical coping strategy of getting help for her mother from mental health services was particularly notable.
Abdul is 19 years old and is the fourth child in a South Asian family of six children. Abdul's younger brother's mental health problems began with learning difficulties in primary school and he has been given different diagnoses at different points ranging from attention-deficit hyperactivity disorder to schizophrenia. He is currently hospitalized, and Abdul's older siblings take the main caregiving roles by visiting their brother in hospital, attending progress reviews and providing reassurance. Abdul, helped by his University education, reads the hospital reports because he wants to understand and be informed on what is happening and because he needs to be able to explain things to his parents, who have little knowledge of English and are less educated. His parents rely on their children or a translator to understand what is being said at the progress reviews at the hospital. Abdul's interview highlighted the importance of a culturally appropriate intervention for ethnic minorities.

Antonia is 23 years old and a University student living away from home. She discovered that her father had schizophrenia when she was 9, although he had been ill for most of his adult life. Antonia provided and continues to provide emotional support for her father. When her sister moved to a different country, Antonia became her father's next of kin and solely responsible for his care, which she found more stressful. Antonia's interview was particularly important because she was the only interviewed participant who cared for a father with a mental illness, providing insight into a previously missing sub-category of participants.
* all names changed to protect confidentiality § all mental health conditions and diagnoses are as reported by participants

The findings of the interviews and focus group discussion pertaining to potential interventions were fed back to a nominal group of interviewed participants who were willing to be contacted for further involvement in the research. Seven participants were contacted and invited to take part in the nominal group. The seven participants were selected with the aim to include a range of perspectives, i.e. people from different ethnic backgrounds, both genders, caring for parents and siblings with different diagnoses of severe mental illness. While all accepted the invitation, only four were able to attend on the day that the nominal group was conducted: Rajini, Arthur, Abdul and Antonia.

The ideas for interventions were presented to the group as a powerpoint presentation (Appendix 4.1). The researcher outlined the proposed interventions and invited the group to comment, before further expanding the proposals with points from the analysis. They were particularly asked to highlight problems that might be faced if they were implemented. After the main ideas had been presented and discussed, they were listed on the screen and participants were invited to individually rank their top five on post-it notes. Participants were also asked to identify in what way these interventions might be helpful for them, i.e. to identify relevant outcomes.

From the early fieldwork it became evident that the study would benefit by discussing the interventions with adult support workers who had experience with young carers, since they have expertise, both in terms of their knowledge of what works for young carers, as well as their understanding of young carers' experiences.

Young carer support workers who had helped with recruiting participants for the study were contacted for interview. Those who were from the same project or team were interviewed together to facilitate discussion. Of the three individuals and three young

carer projects invited to take part, one support worker from a community mental health team (CMHT) and one project did not reply to the invitation. Seven support workers were interviewed, including those who had been in touch with the researcher and their team members who were interested in taking part in the study. All the participants had experience working with young carers or young adult carers. These included:

- a carers support development worker from a CMHT in London
- a mental health carers support officer from a carers service outside London
- a project manager and a project worker at a young carer project in London, with some relevant input from the business support person in charge of processing referrals to the project
- a mental health support worker and a development worker from another young carer project in London

The topic guide for the support worker interviews is included in Appendix 4.2, and the summary of the basic themes that emerged from the interviews is also appended (Appendix 4.3).

THE STRESS PROCESS MODEL FOR YOUNG CARERS

Findings from the thematic analysis of the interview and focus group data are presented within the conceptual framework of the stress process model, in order to investigate the applicability of the model to the experiences of young carers .

CONTEXTUAL FACTORS

These are factors that are part of the caregiver's background, providing the context for the stress process in caregiving. In young carers, these include:

Age-related factors

The differences between those aged 18-24 years, those aged 16 and 17, and those under 16 years, have been outlined in the introduction in Chapter 1. The importance of age as a contextual variable in the model will be seen in the differences between the stress process model for adult caregivers and its adaptation to a young carer population. It was

predicted that age would be associated with specific secondary stressors and moderating factors in young carers.

"*But I think because the needs are so different, lots of times yes this person may be having, you're caring for, may have the same needs but the effect it has on the carer which is often neglected can be so radically different. So if you've got an adult carer who is trying to balance a full time job and pay the bills, it's different to someone who is trying to cope at school with peers not understanding, teachers not understanding, the stresses of being a child weren't necessarily for them the finance, they don't see the issues there as much.*" *Arthur*

Family structure

The structure of the young carer's family and the availability of other family members (well parent, siblings, spouse/partner, wider family) who can potentially share in caregiving is an important resource for the young carer. However, the support that they actually provide is a moderator of the effect of stressors on outcomes.

"It wasn't so much, when I was a kid it wasn't really that much because I could kind of leave it, I could leave it because it didn't have to be my responsibility. I was a kid and I had adults, my grandparents were there, my aunt would go and see him, my mum would go and see him and if I didn't want anything to do with it I didn't have to, but now I don't have that. I am his next of kin, I'm the person, he doesn't have anyone..." Antonia

The family structure and living arrangements often determine who the primary carer will be. Irene identified herself as the main carer for her mother because she was the only person who lived with her. Rajini also lived alone with her mother who has depression. Where there was more than one child living with a parent with a mental illness, it was usually the eldest child who took on the responsibility of the primary carer (e.g. Pauline). When the eldest child moved away, the next sibling took on the caregiving responsibility (e.g. Enid). The exceptions were Antonia and her sister, who were in turn named next of kin to their father who had schizophrenia and thus had responsibility for his care, although they did not live with him. In their case, it was only when each in turn became next of kin to their father that they really had to take on the responsibility for his care.

In most of these families with a parent with a mental illness, the young carer's parents were separated or divorced. However, Clover and Arthur lived with both their parents and shared the caregiving responsibility with the well parent. Clover described it as 'doing shifts' with her father, since he had to work, but Arthur was clear that his father was the primary carer for his mother. The presence of a well parent, however, did not necessarily mean that he/she was most suited to be the primary carer, as seen in Enid's family.

"...my parents are now divorced, they separated when I was about 10, and I think my dad was very bad at dealing with my mum in that he just didn't really realise, and family members have said they would contact him and go "You know, do you think she's not very well?", and "Uhhh...I think she's OK" and they'd come down and be like "Hmmm, no, no, not really". And I think me and my sister are much more aware of when mum is not well, and I think maybe something about being the youngest I think maybe I'm more aware as well..." Enid

Identifying the primary carer in a family was more difficult when it was a sibling who had a mental illness. In some cases, it was clear that a parent was the primary carer (e.g. Naima's mother), but siblings could also take on the role of primary carer, for example, when both parents were working (e.g. Simon) or when parents had difficulty understanding English (e.g. Abdul's older sister and brother). The allocation of the role of primary carer between a parent and a sibling was not always undisputed, and siblings could provide care in ways that parents could not. The balance of caregiving responsibility could also shift with time, with a different family member taking on the primary role .

Participants recognised how much more difficult caregiving might have been without the support of other family members. This support could be provided by a well parent or by other family carers and was evident in a parent's attempts to protect children from burden or in small gestures of affection. If the responsibility of looking after the person with the mental illness was shared within the family, the role was easier. A family could emerge stronger from their experience (e.g. Clover's family). Siblings protected each other and depended on each other for support, whether in caring for a parent or another sibling. A younger sibling could learn how to cope from an older sibling (e.g. Enid).

"Yeah, I can definitely, if not I learn about even more difficulties that are experienced by some of the young people, like one of the fortunate things about my situation is I have loads of siblings, so the responsibility of caring or looking after or looking out for somebody with a mental disorder is not solely on my shoulders but it's kind of distributed to everybody and everybody has to play a role, whereas some people that come to the young carers sessions, these are single children and they are really young, they have single parents as well, they're having to look after maybe their parent who has multiple sclerosis or something like that, so it's very shocking but it teaches me so much." Abdul

Cultural background

While recruiting participants, it was felt to be important to have as diverse a sample as possible to get a range of perspectives on the topic, and particularly to include people from different minority ethnic groups. Five of the participants were from non-European ethnic communities and one had a mixed cultural background. Although participants were not asked to identify their ethnic backgrounds, some spoke spontaneously of their cultural background and its impact on their experiences, while with others for whom it might have had an impact, it was brought up by the researcher. The researcher herself is from a minority ethnic community.

In some cases, the cultural background of a young carer appeared to influence outcomes. For example, it might add to the isolation of the young person (Rajini) or encourage care and acceptance of the person with mental illness by the immediate family (Naima, see below). For three participants, their cultural background had had an impact through the attitudes and beliefs of family members towards mental illness. This could be seen in their reaction to the illness, for example, in suggesting that the person with the illness was cursed. The influence of cultural background could be seen in the impact of family pressure on choices made and in the language barriers raised (e.g. Abdul's parents found it difficult to be fully involved in their son's treatment because they could not speak English). Traditional family roles and pressure from the extended family to maintain the family reputation made it difficult for both Tarun and his mother to separate themselves from his father and make critical decisions for his sister's health. However, a cultural attitude did not necessitate a negative impact. Naima felt that a

family-oriented culture was the reason for her mother's acceptance of Naima's sister's mental illness and her consequent caring responsibility.

"Maybe for my mum because where she grew up, just the country, it's very family orientated so it just helped her, that experience helped her to just take the changes in her child and just continue coz you can't change your family..." Naima

Relationship to the person with a mental illness

Whether the young carer was providing care for a parent or a sibling was another contextual variable that was considered. Those who are helping to care for a sibling are more likely to also have parents who are providing care, whereas those caring for parents may not have other family support. There was some indication that caring for a parent might have more of an impact than caring for a sibling, especially as those in the former category might be sole carers. Enid felt the difference could be seen in the greater understanding of mental illness shown by children of parents with mental illnesses.

"I think probably it's populating the world with psychologists. So everyone I meet with a parent with a mental illness is a psychologist. So I think it means that there are people who have a very good understanding of mental illness and a lot of insight about it in the world to be able to talk about it in that way, different to how a spouse or a sibling would, I think that relationship with your parent being ill is very different and it means that you probably have a lot more kind of compassion about it and maybe, especially in my situation where it's been my whole life, very kind of intrinsic understanding of what's going on and comfortableness with it." Enid

STRESSORS: PRIMARY STRESSORS

Primary stressors are those that are directly related to the mental illness. As in Pearlin's model, they drive the process of stress development.

Unpredictability and threat arising from the illness

One of the primary concerns of the young carer is that the person with the mental illness might hurt themselves or somebody else. Four participants reported feeling threatened or scared by the ill person's behaviour. Simon described feeling constantly on edge, not

knowing what might happen or what the ill person might do. This was a strong theme identified in several interviews.

"*It was either that time or it would be another time but I'd gone back home anyway, and she had taken another overdose. So, like, it was all just like, the sort of thing that I would prefer, prefer the professionals not to allow to happen. So, it was three times in total that I found my mum after taking an overdose.*" *Irene*

"Know how to not sleep and how to lock your door properly. You do get really, I mean you just get used to that feeling of kind of tight chest, and just not sleeping, and looking the whole night. It's just horrible. You just become so much more alert." Mandy

The changes that occur during the course of a mental illness, particularly in terms of the person's behaviour and prognosis, and the difficulty in predicting these changes could leave the young carer feeling constantly on edge, never able to relax.

"But it was difficult to understand like the whole, 'cause obviously it would be one day she would be fine, it's not like it's a constant thing, there'd be very much up and she'd be fine for a month or two and then she would really just plummet and she'd back in to the mental hospital and sectioned. I found it quite difficult to get used to that sort of sense of uncertainty that one minute she'll be totally fine and next minute she'd be rushed straight back in again." Arthur

Prognosis of the illness

Some young carers were concerned about whether the person would have another severe episode, what might trigger that, and the likelihood of full recovery. For example, Rajini was worried that her mother might be hospitalized, and that she could lose her mother to the illness. While some young carers had learned to recognise that recovery is a long process, others had been disappointed in their hopes of a full recovery, or felt despondent at the length of the illness. Antonia explained that the episodic nature of the illness can make the recovery process emotionally very difficult.

"*Looking back I think it was, it still is, that she's never actually going to be well and she's never going to be off the tablets. Is it something that she's going to be on for the rest of her life? Am I always going to have to cope with the fact that she's going to have good months and bad months and yeah, each year is going to be different, and the fact*

that she can't cope with my stresses or any stress at all. I think that's my biggest worry at the moment and it probably was back then as well, because you can't see the end of the tunnel." *Clover*

Being 'sectioned'

While it was in some ways a relief to know that a loved one was safe and being looked after, the whole process of detention under the Mental Health Act 1983 (being 'sectioned') was found to be very stressful, but not for all young carers.

"As well as getting my head around about the idea of my mum being in effect locked away for her protection as well as then having to deal with well what my friends say, I found quite difficult to deal with." Arthur

"I think in a way it probably sounds a bit weird but when she was sectioned I knew that, it was almost a sense of release in comparison to what she, that sense of living on the edge..." Arthur

*"...I think it's a really bad way that it's organised, and I don't know why you would want to call a policeman to come and deal with somebody who is mentally ill. And like this time when my mum was ill they took her, there wasn't any room at the local hospital, they took her to D*** which is about a half an hour drive a way in the back of a police van with police men and it's like well that's not the way it should be, this is sending out very odd messages about what it is to have a mental illness if, when somebody is being seriously mentally ill you call the police and not a medical professional" Enid*

Loss of relationship with the ill person

Participants described the feeling of loss, of losing a person to the illness. The loss of the relationship that had existed previously with the ill person occurred in more than half of the narratives. This could change if the person recovered but could be repeated with episodic illnesses. They described it as the person they knew not being there anymore. Antonia portrayed the change as scary to watch, yet fascinating, while Irene compared it to bereavement. What was important, as Irene pointed out, was knowing the difference: if they had had a chance to know the family member when he/she was well, then they knew the difference when the person became ill and could feel the loss.

*"And because M*** [her sister] didn't really know dad like I knew dad, it almost as though she wasn't as affected because she didn't see the huge personality change because she was never really close to him anyway, so she just realised that he was weird, that he had changed and he was weird, but she didn't have a strong relationship with him so she didn't kind of sense that loss that I felt, like I'd lost my father, and I think that was the hardest thing." Antonia*

However, the impact of the loss of the relationship with a sibling is also likely to be less severe than the loss of the relationship with a parent. Some of the young women described the loss of the mother-daughter relationship (although there were also young women who were, in their words, 'daddy's girls') as the loss of a special bond. Clover, comparing her experience of her father's depression with that of her mother's depression, felt that losing her mother was harder because she was closer to her, although caring for her mother did bring Clover and her father closer together. Even Antonia, who shared a close relationship with her father, felt that it must be harder to lose a mother to the illness.

"So it's very upsetting when she's ill and she's not herself, and I think part of it as well, I have a very good relationship with my mum but when she's ill it's like she's gone on holiday for 3 months or something, and actually you need your mum, and if she's not being your mum then that's not nice 'cause you think 'Well this isn't right, I should be calling you up and telling you mundane things about my day and you'll be deeply interested and not telling me to shut up and not call you, that', that it's difficult." Enid

STRESSORS: SECONDARY STRESSORS

Secondary stressors are derived from primary stressors. Unlike in Pearlin's model, problems related to caregiving are described here as secondary stressors, because they are not inherent to the illness.

Lack of choice

Young carers tended to have little choice in taking on a caregiving role and this lack of choice could be understood as a secondary stressor. Of the nine participants who were caring for a parent (including one who cared for both a parent and a sibling), eight were the only person available at that point to take on the caring role. Three had older

siblings who had moved away and two of these older siblings had previously been the main carers. The majority of the parents with mental illnesses had separated from their partners. The exceptions were Arthur's parents, both of whom had health problems, and Clover's father who was looking after her mother but also had to work.

*"She had a financial stress I think that did it really, so that just somehow into this depression really quickly, came really quickly. And obviously by that time she wasn't with my dad, she's not been with him for years and years, and my brother'd moved and her family all live in **** so it was just me." Irene*

On the other hand, all those who were caring for siblings had parents who were also providing care. Nevertheless, Simon saw himself as the primary caregiver for his brother, since his parents were working and he had always looked after his younger brothers. His situation seemed a little contradictory, because he said he had no choice and that it was not something he wanted to do, but he also said that if he had minded doing it, his family would have found a way to work around it. Beatrice was the youngest of six children, but saw her father and then herself as the main carer for her brother. However, she was the only child remaining at home with their parents when her brother returned from the hospital. Thus those who were present and available tended to have less choice in taking on the caring role.

Caregiving can impose other restrictions on choice. Participants in the focus group identified restrictions on social activities as a particular difficulty, made more difficult by a lack of understanding, which made young carers feel different from their peers. Some young carers felt restricted in their ability to move on to their next step in life (e.g. University, work, living away from home). This issue of choice in moving on was specific to young adult caregivers. The issue was explored in depth with one participant, Arthur, whose experience with young carers' services and from meeting other young carers provided insight into the transitional stage between school and adulthood. He felt that few young carers feel able to go on to University or to move away from home because they feel tied down by caring responsibilities. He had worried about how his parents would cope if he moved away, and did not want to leave the safe environment of his young carers' group, where he had been accepted and understood. It was not until he was supported by a tutor in thinking about University that he was able to explore it as an option. Similar feelings of restriction were seen in two other narratives.

"So like there was someone actually from the young carer project where I live who was speaking to David Cameron, she says like 'I want to go to university but I can't, because I can't leave my mum' and I think that's the issue which needs to really be addressed. In terms of how do you provide the support and make sure actually they feel like they can..."Arthur

Participants in the focus group felt that they had little control over their futures, that there were things they could have done but were prevented from doing by their caring situations. Three interview participants who did move away from home felt guilty about leaving the person they had cared for.

"And it was really hard going from that situation where I was looking after her loads and then suddenly I was kind of breaking free and going to Uni and enjoying myself and then coming back and realising that she'd got really bad and I hadn't been there to help her." Clover

The nature of the caregiving role in mental health

The nature of the caregiving role is different when somebody has a mental illness. The role can be difficult to establish, irregular, and can change as the illness changes. It can also be difficult to know how the ill person is feeling and how to provide emotional as well as practical support for them.

One of the characteristics of mental illness highlighted by participants was the unpredictability described earlier as a primary stressor. This is accompanied by changing demands in the carer's role and in the relationship between the carer and the person with the illness.

"I think the difficulty I had is kind of find that distinction between when is she well, when isn't she well, when does she need my help. There were points when she was literally lying in her vomit and I had to call an ambulance, but there were other points when she was very able, and probably more able than me so I really don't know. It's a very ambiguous term carer to me, I really don't know how to define it, I think there were points when I was caring for my sister and there were also points when I wasn't doing so good by her." Tarun

Participants felt there was a difference in caregiving experiences between mental and physical illnesses; with mental illness, it is harder to know how the person is progressing or feeling, or how to deal with it.

"When someone has got a physical illness, like with her back you can see, physically see how she's doing. When you've got a broken arm you can see that it's healing, you can see when you're having good days, bad days. When it's mental you just don't know, there's no, because you can't see anything you don't know how she's feeling and then there's times she won't open up, she won't talk, there's times when she's so depressed and she's so out of it, upset and then she will all of a sudden break down..." Pauline

"But yeah, I think there is a difference between somebody who has a disability that we can understand properly, say they can't use their legs or something. We understand that, and we know how to cope with that, and it's probably just as emotionally draining, but we know how to deal with it. With mental illness we don't know how to deal with it, and I think it's a lie to say that we do because we don't even know what drugs to give people." Mandy

The demands on young carers ranged from an "as-and-when carer role" (Tarun) to constant attention to the needs of the ill person (Pauline). A young carer's role could also vary in intensity over the course of the illness. The responsibilities that comprised a young carer's role were mainly of two kinds: there were those that were more physical or monitoring, and those that were more emotionally supportive.

The first category was concerned with physical tasks and material needs, and included helping the ill person physically, keeping house, translating and explaining information about an ill sibling's care for the benefit of the parents, visiting a loved one in hospital, providing respite for the primary carer and caring for other siblings in the family. It also included a monitoring role, for example, making sure the ill person was eating, drinking, and taking the proper medication, accompanying them to appointments, and keeping them occupied. This included regularly checking up on the ill person, constant vigilance to prevent loved ones from hurting themselves or misusing alcohol and other substances, or dealing with emergency situations like overdoses

"She wouldn't cook, or do anything. She wouldn't open her letters. She wouldn't do anything at all. I had to go and buy her food, buy her like, canned stuff so that it didn't

go off and all that. Like make, her, like make arrangements with her, like 'I'm gonna come to dinner, this evening. You have to make dinner, you have to get up, have a shower...' like, she wouldn't wash, she wouldn't do anything, like a human does. She just wouldn't function. Through the whole, like almost the whole year, just gone." Irene

"...but like I said the main thing is he might get up in the morning and I would have to keep an eye on him at all times, make sure he doesn't go into some sort of trance you know have to be around him all the time, I couldn't leave him alone for 2 minutes. I had to keep an eye out to make sure he didn't hurt himself or someone else you know." Simon

Participants felt that the key to caring for somebody with a mental illness, however, was emotional support. Arthur, whose parents had physical illnesses in addition to his mother's depression, could compare the two and identified the emotional care that was needed in the case of mental illness. This included acting as companion and confidante, keeping the person calm and avoiding upsetting them, keeping the person occupied, and keeping things normal at home to allow his mother to to readjust after hospitalization. Significantly, the necessity for a young carer's support could be seen by the effect on the parent when it was absent.

"It's more sort of emotional support because I'm the only person that's there for her, so... I don't even know what I do really, it's more sort of if I'm not at home and I come home at the end of the day, my mum she just looks really bad and she just tells me that she's been feeling really bad and the house is a mess..." Rajini

Some young carers felt they were having to cope with responsibilities that should have belonged to an adult. This included both emotional and practical responsibilities, and tended to occur when parents could not deal with things they would normally be expected to do, or when they depended on a young carer for advice. This could be stressful and annoying for the young carer. Beatrice described it as being treated like "the eldest male" while Clover felt like she was the mother in their situation.

"Extremely stressful, yeah really stressful because I mean, I was 16 and found she hadn't paid these bills for months and I was getting calls from like bailiffs and debt collectors saying she hadn't been paying this, she hadn't been paying that, and she won't deal with it all and you expect your parents to deal with these things, you don't

have an adult that you can turn to so what the hell do I do, so you just have to get on with it." Pauline

Lack of recognition of the young carer's expertise and inclusion in treatment

One of the key aspects to the young carers' role is their expertise about the people they look after. Participants were aware of the nature of the illness and its symptoms and could recognise when the person was becoming unwell. They were familiar with the patient's full history and could describe what was going on to the psychiatric team and other services. They had learned by experience what would help and how to deal with the person. This expertise was frequently compared to that of the health professionals.

"...because you can sense when she's getting more and more down, she becomes more withdrawn, she would be sleeping in all the day, would stop doing things, you could tell just by the tone of her voice that she was heading downwards in terms of her mental well being." Arthur

Their role as experts meant that young carers sometimes had to take the initiative to get information or to voice their concerns about the person for whom they cared. Conflicts arose when the young person's role and expertise were not recognised by healthcare professionals, sometimes leaving the young carer feeling rejected. Recognition of their role was seen as helpful. The focus group discussed the need for their knowledge and their role to be recognised by staff, and for staff to take into account what the young carer was saying, particularly when they were voicing their concerns about the ill person, for example, when the ill person was suicidal.

The focus group raised the difficulty of patient confidentiality, when services would only deal with the patient. For them, it was particularly difficult when the person with the illness was unwilling to seek help and the carer could recognise that the person needed help, but services could not provide help or information without the consent of the person. The participants felt that professionals needed to listen to what they were saying and respect them as carers.

"What would have helped? I think a bit of recognition that actually it's people's children, especially if it's a single parent, who know the most about what is going on and they will know the best way, they know how to deal with their parent, they know

when they're ill, and I think a bit of understanding that actually they're the best people who can deal with it." Beatrice

Stigma and discrimination

Public fear, stigma and discrimination associated with mental illness can affect the support accessible to a young person. Mental illness can be difficult to discuss with other people, reducing access to support from friends and others outside the family. Naima felt she had been stigmatized at school because of her sister's illness and had not been able to bring friends home. She had had to change schools. Beatrice found that her friends were scared to come around to her house because of her brother's illness.

"And then there'd be the other thing, like most of my friends knew that he was ill but didn't really like, everybody that doesn't know anything about schizophrenia thinks that they're going to stab them all the time or something, and so my friends were always really scared about coming round my house. And like they'd always like ask me if he was going to come into our room in the middle of the night and attack us, and I'd be like "Why would he do that?" That was really difficult because of the stigma attached to it, and people wouldn't come round." Beatrice

Young carers found it difficult to talk outside of their families about their experiences and about mental illness. While Irene and Rajini felt they could discuss their situation with friends to some extent, and for Simon it had never been a secret (albeit after an initial urge to conceal the illness on his parents' part), three others felt it was not something they could share with their friends. Naima described her family's attempts to conceal her sister's illness from other people to protect her. Antonia described it as living a double life, because her friends were unaware that her father had schizophrenia and while her teachers knew, they would never talk about it with her, making her home and school lives very separate.

"...and I think especially growing up as a teenager, the fact that it was never talked about, like my friends had parents who had cancer and the teachers would always say "Are you Ok? Do you need anything?" but it was never the same with me. Like all the teachers knew my dad had schizophrenia because it was a small town that we lived in and no one would ever ask "How's your dad doing? How are you? Are you Ok?" like none of that..." Antonia

Financial difficulties

Some participants were affected by their parent's difficulties with finances and benefits. Three mothers had difficulties budgeting and managing money, and Irene's mother got into trouble about her benefits. The first three mothers would spend money regardless, which resulted in two of them spending their children's money. This meant that Pauline and Rajini had little control over their own money.

"...but it's only I think since she got ill she cannot deal with it, she just spends it like she's just living in the present without thinking that tomorrow's going to come, so I just said to her, I did actually say to her, "This year I want to have complete access to my account, I don't want you to take any money out". And then at first she said 'yes', but then she's just been ignoring me so but I just thought, no, there's no point arguing about it any more I guess. There's nothing to do about it." Rajini

Rajini felt angry about this and worried about paying back her loan. The financial issue was emotionally difficult for her and induced a feeling of hopelessness. Pauline had to start working at 16 because there was no money and her mother's tendency to borrow from her continued to make things difficult even after Pauline moved away from home. Huy's mother's difficulty with budgeting meant that both of them struggled when the money ran out. It also could have an effect on the person with the illness, e.g. Rajini's mother's difficulties with money were detrimental to her own mental health and Irene's mother's became ill again with the financial stress.

MEDIATORS

Mediators are those factors which change the effect of stressors on outcomes, resulting in variability in caregiving experiences. As with Pearlin's model, the main mediators found in this study are coping and social support.

Coping strategies and resources

Based on their own experience, the advice that participants would offer other young carers focused on strategies such as actively seeking help from services and support networks, having an independent activity (e.g. a hobby), accepting the situation and trying to remain optimistic about the future, and not blaming oneself. This indicates that

young carers recognise the importance of and need for positive coping strategies to deal with the stressors

"I think you have to communicate the problem that you're having and you don't get anywhere by being conservative about it" Enid

"*The only advice I can give you is don't hold it in, don't try and deal with it on your own because it's too hard and you can't.*" *Pauline*

Young carers used both problem-solving and emotion-focused coping strategies. A few of the young carers used the cognitive strategy of avoidance to deal with their parent's illness, trying to distance themselves mentally from the situation or to block it out.

"And also because I am older, I just didn't like the reality of the situation so I just avoided going there for, you know, a long time really." Irene

Others found ways to "escape", whether it was to remove themselves from the situation for a short time (e.g. work, studies) or to vent their emotions (e.g. writing, playing computer games). As Pauline described it, she just "had to get away". This method, however, did not work positively for all those who used it. For example, Irene tried to keep herself busy, to the extent where she began to get ill.

"...but, mainly, just...well, I tried to occupy myself, that's how I coped through that time. But eventually I was so busy, all the time, I was getting run-down and ill from doing that. And I couldn't have a spare minute. I would start to get really anxious and panicky." Irene

"It didn't affect it [her studies] at all really, because I just made sure, because I guess the only thing I had apart from my mum was studies, so in a way it was good for me to have something different to focus on, so I just focused on that and I didn't let go I guess." Rajini

Some of the young carers responded emotionally with anger or frustration at the person or the situation, and Simon described the need to release his aggression.

"I think it was because he wasn't there, like he wasn't my dad, he was this freak that I didn't know, and I was angry at that person and I wanted him to go and I wanted my real dad back, and I think I was angry because I couldn't do anything about it, it's not

like a physical illness where if you take the medication then you know you'll see an improvement, like it took so long." Antonia

Young carers also used a variety of cognitive methods of coping, including accepting, questioning, and rationalising their situations, thinking positively, and deciding to change things.

"'Cause my mum was abused she can't, even now my mum can't come near me, she won't give me a cuddle, my mum doesn't do female contact at all. She's not, she's always treated me and my brother completely differently, which now that I am an adult I accept, I don't really care any more but growing up it was always hard..." Pauline

Finally, some participants used active coping strategies to deal with the situation. Five of the former young carers described how they just got on with it and did what they needed to do. Clover, for example, focused on trying to find ways to help her parents, but found it harder to help herself. Beatrice was able to talk things over with her sisters.

"To be 100% honest, you go in to that mode where you just blot it all out and just deal with it." Tarun

"I don't know, just got on with it, kept calm and carried on" Beatrice

Enid sought help from mental health services, getting them to come and help when she could no longer cope with her mother. She also described not coping as an active strategy, since she was able to recognise when she could no longer cope and just had to allow things to happen. She also recognised that it might be harder for those caring for chronically ill patients to cope, because they had to deal with things every day, whereas her mother's illness was more episodic.

"I think even when things get too much, there aren't really any options other than to kind of just let it happen. And maybe now I have a kind of higher tolerance for what is too much, because I have been at that point and been like 'I'm not coping' and then just not coped and let things happen and it's been all right, it's not been nice, but it's been ok." Enid

Where the caregiving relationship is reciprocal and recognised as such, it could be an additional coping resource, as in the case of Rajini. Young carers frequently shared a

close relationship with their ill parents and, although there was a change in the relationship when the person was ill, the relationship usually continued to include positive aspects and reciprocal care and concern.

However, this was often dependent on the health status of the ill person (usually a parent). More than half the participants felt a change in the relationship with the ill person, but whether this meant that the caregiving relationship was no longer reciprocal was not as clear. For at least two of the former young carers, when their mothers were very ill they were no longer able to look after their daughters as they had done previously.

"Yeah because if I have any problems with the University or if I'm worried about what courses to take or what to do when I'm older I always talk to her [her mother] and she always gives me advice. Often she changes her advice but she always gives advice, always talks about it with me so I can talk to her about everything I need to really." Rajini

"Before May last year I felt I could talk to her about anything, and she was really good, like source of all things you want out of a mother, really. But now, but she wasn't for so long." Irene

The impact on some young carers' social lives, skills and relationships suggests that their coping resources may be reduced. Two reported feeling different from other people and two felt that their experiences had had an effect on their relationships with other people.

"I can read people in that I can see if they're being truthful to me, but then at the same time it affects my ability to trust people, I don't trust anybody. So you know, it's certainly affected my relationship with family. If any of my cousins or uncles or anyone says anything I was like 'what about this?' and 'what about that?' and I always end up making them into a liar." Tarun

Six out of the 14 young carers who were interviewed reported an impact on their social lives as a result of their experience. Five of them were limited in different ways in their ability to go out and socialize with their peers, either because of their caregiving responsibilities or because of the family member's illness. Participants in the focus

group were also limited to some extent in their social activities. Socialising was made more difficult by a lack of understanding, which made young carers feel different from other people. The difference in levels of stressful situations, for example, was an area in which it was difficult for young carers to relate to their peers.

"Well, to be honest, not so much, because when he started first getting ill I couldn't see them that much and then they went off to university. And because I'm home all the time, because I was home and because I don't have a job and because I don't go to school or university, I haven't had a chance to make new friends, so there's not much of a social life there anyway. But before like I said when I still did, before my friends went to university, a lot of the time I couldn't because I had to stay and care for him. So it definitely has an effect, yeah." Simon

While adult carers may also face isolation, young carers are more dependent on their family, particularly their parents, for their social circles. One outlet might be their friendships at school, but the impact on their education and the stigma they face can prevent this, resulting in more isolation.

Social support

Aspects of social support can be important moderators of the effect of the stressors on caregiving outcomes. Participants' responses indicate the difficulties faced in dealing with situations without adequate support from others. This included working out what would be best for the ill person, dealing with emergency situations or other situations connected with the person's illness, and taking time for oneself.

"It was frustrating at times because sometimes we found ourselves snatching aerosol cans from her in her room and it was getting quite mucky in terms of we really didn't know if we were doing the right thing and it was confusing, we didn't know what we were doing..." Tarun

Young carers found support from three sources.

Family support

The support of other family members in the care of a person with mental illness was felt to moderate the effect of caregiving on distress. The support provided by family tended

to be either practical/instrumental (e.g. looking after the young carer's practical needs) or emotional needs (e.g. talking about the things that are frustrating). Informational support was rarely provided within the family, possibly because discussing the illness within the family was difficult, possibly because families themselves have limited information. The amount of family support available usually moderated the amount of caregiving responsibility a young carer has (e.g. Antonia, Enid, Clover, Irene, Abdul) but it also moderated the negative outcomes of caregiving responsibility (e.g. Pauline, Antonia) or the illness (e.g. Arthur, Irene)

*"If it wasn't for his [her partner's] support I think I probably would have gone mad. But I've built up a network on our own, it's only having what you've got isn't it and without my brother and without L**** [her partner] and my dad it would be mad." Pauline*

"*It wasn't so much, when I was a kid it wasn't really that much because I could kind of leave it, I could leave it because it didn't have to be my responsibility. I was a kid and I had adults, my grandparents were there, my aunt would go and see him, my mum would go and see him and if I didn't want anything to do with it I didn't have to, but now I don't have that. I am his next of kin, I'm the person, he doesn't have anyone...*" *Antonia*

Young carers who had family support (e.g. Mandy, Arthur, Abdul) could recognise the impact that a lack of support would have on the level of caregiving responsibility and on outcomes. The experience of those participants who were sole carers and who lacked family support at some point in their caregiving could be contrasted with those with family support, and the impact seemed greater with sole caring. Irene could contrast this time when she was her mother's sole carer with the previous time her mother was severely ill, when Irene still had her family around her, and she felt the impact was greater the second time. Rajini's sense of isolation, intense relationship with her mother, and her consequent distress at the thought of losing her mother to the illness was evident in the interview. Antonia felt that her responsibility as next of kin and her father's sole carer was more stressful than before. Tarun felt unable to live his own life because his mother would be left alone.

"*So I think young carer is good but I think maybe it should be distinguished between somebody who has no support and somebody, like the cases of somebody who has no support at all and somebody who has a lot of support. Like somebody who has no*

support will need extra help in order to live a normal life, somebody who has lots of family support will just need, I guess, more information." *Mandy*

However, family members were not always a source of support, distinguishing social network from perceived social support. It could occasionally be frustrating when it felt like a family member was not involved in the experience (e.g. Clover, Beatrice, Enid's sister). Antonia was closer to her father and felt that his illness had more of an impact on her than it did on her sister, so she could not derive any comfort from talking to her sister, nevertheless she felt her sister's absence after her sister moved away. Furthermore, as mentioned earlier, a young carer could be left feeling abandoned and unsupported when an older sibling moved away from home and seemed less affected by the mental illness. Antonia described how she was less likely to confide in her family as a teenager, and how she was able to talk more openly about her caregiving difficulties and experience as an adult with the rest of her family.

And also at that time my brother had just left to go to university so he wasn't involved at all and to be honest, I don't even think he knows half of what happened and I've never really been able to tell him." Clover

Support from health services

Young carers' experiences of mental health services indicated that they could either be a source of support or a stressor, and have an impact on the outcomes of caregiving. The support sought from and provided by mental health services in this study was primarily information.

Some young carers did not feel adequately supported by mental health services in caring for the person with a mental illness, while others felt that there were aspects that could be improved. Problems included lack of information, disappointment in staff and services, the need for involving the patient's family in care and listening to their concerns. Mental health services could be confusing and complicated for young carers as they tried to navigate the system, particularly when services seemed to work differently each time. A lack of continuity in treatment, need for information-sharing between professionals, and a lack of direction could also make the experience difficult for the family.

Some participants' negative experiences centred on their perception that health professionals did not listen to them or address their concerns. This occurred in primary care, secondary mental health services and emergency services. Participants felt that staff should be more involved in anticipating risks and preventing crisis situations, to be responsible for patient and carer safety, rather than increasing the distress already felt by the young carers.

"*Well not straight away, I think that's always the frustration is that every time she was ill it seemed to be a different kind of system, you didn't know who to contact, you didn't know how to get involve people, I mean where my mum is they have a crisis team which we call the 'no bloody use in a crisis' team. They are fine after she's been in hospital but we don't need you now, it's good that they go out every day and see her afterwards but you think 'you're called the crisis team' and you call up and they go "Well she's not one of our patients". "I know she's not one of your patients because she's been well but now she's not", who do I call and it's just very difficult.*" *Enid*

"They don't listen to you, as far as they are concerned you're just a kid, you don't know what you are talking about. One doctor actually said to me have I been to medical school. It's like no, but spend a week living in my house and you will see what it's like, but no, absolutely useless the doctors were." Pauline

There were also positive instances in each interview where the family or the young carer had received support from services, whether it was general practitioners (GPs) referring patients to the appropriate service, "good" CPNs (community psychiatric nurses), or the provision of supportive services like counselling and carer services through the local authority. Other examples included: being able to check up on the ill family member and express concerns, flexibility about a child visiting her mother in hospital, help for the patient that was immediate or preventive, and showing sympathy and understanding. Naima had a particularly good experience with mental health services when her sister was in hospital. Staff solicited her expertise, involved and listened to her family, and referred her to a group for children who had a relative in hospital. Involving the family, listening to them and informing them about treatment and progress, making regular contact with the young carer and suggesting how to cope with the illness, and explaining the illness, treatment and sectioning, were all examples of practice that the young carer found helpful and positive.

"*And I think that was the first time, I came out and I cried with relief, I was just so happy to have someone actually pay attention to what I was saying and care and actually feel like I was helpful. And I was just like I don't know why it's taken so long for someone to see that me is the person who spends the most time with him, I know his behaviour and I know when he's not well, I just never understood why they didn't value that. And so yeah, B**** was the only place where I actually felt that they cared and they understood, they kind of , it wasn't just another patient with a family to have to deal with...*" *Antonia*

The information which the former young carers felt would have been useful related to three stages of the illness: (i) information relating to the illness itself when the person became ill or began to receive care, (ii) keeping the carer informed about what was happening during treatment, and (iii) information for the family when the person was discharged from hospital on what to expect, how to care for the person and who to call for help.

Support from young carer projects

Participants' reports of the positive impact of young carer projects indicated that these were an important source of support. Each participant had found different aspects of the young carers service suited to their particular need.

"*We don't do all the things with them. I don't feel the need to be around other young carers or things like that, I don't, do you know what I mean, I don't like pity and stuff like that. But H**** [project worker] I do get on really well with and we used to meet up every couple of weeks or whatever, every couple of months when things were stressful and it's just like an outlet, d'you know what I mean. They have been great and she's helped with a lot of things that I was dealing with my mum and that.*" *Pauline*

Six participants had received support from young carer projects, one had received support from a carers service, one had received support both from a carers and a young adult carers project, and one had volunteered with a young carer project. Seven of them had been recruited to the study through their carers/young carer project. Young Carer Projects provided a range of services which young carers found helpful. These included trips and activities, one-to-one sessions and counselling. Participants valued the opportunity to meet other young carers, to have an adult to talk to, to have somebody

who seemed to care checking up on them, as well as having an outside focus and some time off from their caregiving. Staff at Arthur's young carer project had acted as an advocate for him, coming to his school to explain Arthur's situation to his teachers, to solicit support and to create awareness about young carers in the school.

"Yeah I really enjoyed it, it was the sort of thing where, especially between, so I benefitted most from it between 14 and 16 I think, having that sort of regular chance to have a break, meet other young carers who have experienced similar issues, also having someone there who could come in to school if things were bad, who could help trying to explain to teachers and make awareness, was something really beneficial." Arthur

Individual participants had found different elements of young carers services to be particularly suited to their needs and tastes. For example, Simon did not find counselling helpful but enjoyed the trips, whereas Pauline did not enjoy meeting other young carers and going out as a group so much. Having somebody to talk to, seemed to be the feature of belonging to a young carer project that was most valued.

The positive emotional effect of the services could be seen in young carers' descriptions. Arthur described it as a place where he felt safe, with people who could understand what he was going through. The benefits for him of attending the project were clearly visible when his attendance at school improved. Naima found that the young carer project had helped with her anger by being an 'outside focus' in a life that revolved around her sister's illness. Both she and Pauline felt that it had acted as an outlet when things were stressful for them. Volunteering with a young carer project helped Abdul to develop a better understanding of mental illness and care giving. Participants who attended a project described at least one aspect as being helpful for them. The exception was Huy who said little about the young carer project and seemed to have been unable to take part in their activities because of his college work. However, the projects did not address all individual needs. Rajini's experience emphasises the particular need for isolated young carers to be identified and supported, to avoid their isolation continuing within the project.

"I mean there was a group of boys who just all just stuck together, there were a group of girls who all stuck together and to be honest they seemed to be having, I mean aside from, I don't know what their caring responsibilities were, aside from that they seemed

to be, from what they were talking about, the fact that they had gone out clubbing or that they had gone out with their boyfriend the night before so and so, they seemed to be having quite similar life to other people I have met at school who weren't young carers so it just seemed like ok, I've just come out of school and I've come into this and it seems exactly the same." Rajini

Barriers to getting help from services

While actively seeking help could be a young carer's coping strategy, there could still be both psychological and practical barriers to getting help for the person who was ill. In some cases it was the young carer, in others it was a family member who contacted health services to ask for help. In one case the school was instrumental in putting the ill young person in touch with the appropriate service. Some participants had been wary of seeking help for their family member. Rajini and Pauline were afraid of getting help because of their fear of being separated from their mothers. Huy went through conflicting emotions because, while he was afraid of what might happen to his mother and was reluctant to seek help, he found he was also relieved when she was admitted to hospital, because he was able to escape from his situation and his mother was going to get the care she needed.

Even when steps were being taken to access services, there could be obstacles to getting help; for example, Tarun faced difficulties getting through to the crisis team to get help for his sister who was abusing solvents. Office hours and the tendency, according to Enid, for emergencies to occur out of hours was another difficulty. There could be language barriers, as in the case of Huy's mother whose difficulty with English meant that she could not express herself clearly to the psychiatrist. Enid described the need to find the right terms to explain what was happening to the psychiatric team. Finally, the difficulty in getting help could arise through the patient, either because the patient does not want the carer to be involved, or because the patient does not recognise their need for help.

"...but when you're talking about somebody who is in your family, you don't immediately go "Oh they're being aggressive" or interpret it as aggression, you're just like "They're being mad", like "that's what it is, why can't you come out and deal with that?" I think finding the words to be able to explain to somebody exactly what's going

on is something that really helps and something that they respond to and understand what's going on." Enid

Some of the participants posited that getting access to help earlier, both for the person with mental illness and the young carer was important. Enid highlighted the need for early intervention rather than waiting until the person had become severely ill and emergency action was needed. Huy also emphasised the need for getting help sooner because of the potential impact on the young carer's mental health by delaying support.

Access to services for the young carer was mostly through the local authority, sometimes through referrals, occasionally through school, and in one instance through the police. Although the number of young carer projects had been growing (at the time the research was conducted), not all participants were aware of the services available and some were unsure about the criteria for accessing the support of a project. It was suggested that information about young carer projects could be disseminated through television and social media, with active engagement with families propounded as being more helpful than just information available. Earlier access was thought to be helpful. Rajini was over the worst of her experience when she was put in touch with a young carer project, but caregiving had had an impact on her social skills and left her very isolated, which meant that she could not benefit fully from the project. Moreover, there was no discussion about being a young carer between members of her group, many of whom were children younger than her, which meant that there was no one with whom she could share her experience.

Finally, the issue arose of the route through which young carers services were provided. While Beatrice felt that it would have been helpful to have an adult to talk to, she felt she would not have used a young carers service unless it was at school, primarily because she would not have made the effort to go elsewhere. Huy also suggested the provision of young carers services through schools, because his mother would not have allowed him to attend the activities provided by the service very often, although she did not object to him attending activities at school. Providing services through schools might widen access to more young carers.Finally, as one participant pointed out, providing services for young people tended to be a reactive response, rather than intervening to provide support at an earlier stage.

This suggests that the pathway to getting help for somebody who is ill needs to be considered when planning support for young carers of people with mental illnesses, since getting help for the person with the illness usually results in helping the young carer. Similarly only some young carers had support for themselves, and sometimes the support only happened when the need became desperate.

OUTCOMES

The following were descriptions of the outcomes of caregiving as a child for someone with a severe mental illness. Data on the types of outcomes were provided via the focus group described earlier as well as the in-depth interviews.

Stressful/negative outcomes

Young carers' descriptions of their experiences were indicative of the stressful nature of caregiving and of its negative outcomes - 'chaos and destruction', 'my whole world is falling apart', 'exhausting' - a stark comparison with the relief felt when the person is better.

"I think it's always difficult, and I think, maybe now, I find it upsetting and sad but not, I think this time when she was ill was the only time where I hadn't sort of been there while she was ill and I think if you were just with somebody, with your mum who is obviously very ill and it's really hard and it's hard work and you don't get to sleep and this sort of thing, then it's very emotional and very difficult." Enid

Figure 4.1. shows the immediate responses of young carers' in the focus group to their caring experiences. Many of the comments describe aspects already delineated: caregiving was seen as a responsibility, there was little choice over their future, and they had to make sacrifices over their own lives. Caregiving could be a distraction. Feelings of depression, stress, confusion, desperation, paranoia and tiredness were noted. There were also feelings of inadequacy, when they did not know what to do or felt like they were not doing enough.

In the second exercise, where participants were asked to write on separate post-it notes what they liked and disliked about being a young carer (Figure 4.2), they also described a gamut of negative feelings: anger, depressing, draining, stressful, painful. The young person feeling responsible and feeling unwanted were both mentioned. Two participants

wrote of being scared for different reasons. Stressful, guilt, blame and depressing were the most frequently noted feelings.

Fig. 4.1. Focus group exercise I

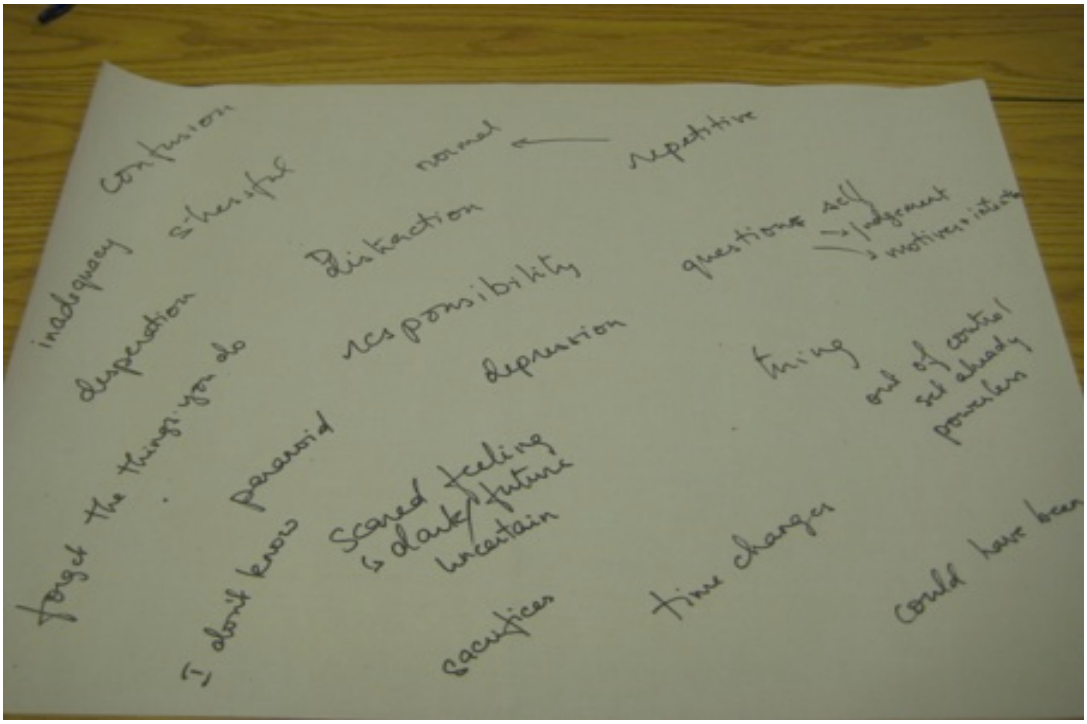


Fig. 4.2. Focus group exercise II

However, the outcomes or impact of caregiving can change and need not remain negative.

"It is, when it first happens it's devastating because normality has gone, and what you knew is never coming back. While she's getting treatment it is relieving because finally, you know, somebody's seeing what you've been seeing and you realise that you're not losing your mind as well, something was wrong with her. And once they are well it's rewarding when you see them happy, even though it's not every day and there will be ups and downs, yeah, it's nice to see them have peace with themselves after everything." Naima

Blame and Guilt

Other outcomes mentioned in the interviews and focus group were blame and guilt. One interview participant blamed herself for her parent's illness. Some also blamed the person with the illness for developing the illness or for their behaviour. Some felt guilty about decisions they had made, or for not providing sufficient care for the ill person. There were also feelings of guilt at moving away from home and moving on with life.

"*I think I was just very scared, that was the only feeling I had, I was absolutely petrified that she was going to die. And again, there was no reason for her to feel like that, so I was angry as well because I was like 'What gives you the right to take all these tablets when you've got to look after me, because I am your child?*" *Clover*

"*...But now it seems to be his own doing, because in the past he'd had episodes where he'd just stopped taking his medication and therefore he'd get ill, or he would start, he would take something, and now that's what it is.*

"...so from now I don't see him really getting 100% better unless he does something about it, because when dad's well you wouldn't tell he had an illness, when he's on medication he's like [a] completely normal person." Antonia

Focus group participants also experienced feelings of guilt ('Like it's my fault it happened') and blame ('I feel like I dont[8] do enough').

[8] Spelling as given

"*Some people have the habit of sort of like blaming it on you, the actual carer, blame it on the carer that is looking after them, sort of like 'you're the reason why I'm not this that or the other'...some people are [like this?]*

...Feel like you don't know really, when you can't really cope and you're probably doing as much as you can, yeah. I think when things are bad, you know" *FGD*

Bullied at school

Two of the participants and one participant's brother had been bullied at school, and another felt she would have been bullied if she had been a less strong personality. This has been seen previously where those supporting people with mental health problems can be cautious about seeking help outside the family and remain hidden from services because they fear stigma, discrimination or bullying (HM Government, 2010).

Impact on work and education

For some young carers, caregiving had had a negative impact on their education because they had missed school or found it difficult to work at home. It could have a disruptive effect when, for example, young carers had to deal with crises in the middle of examinations. However, there were exceptions: Mandy saw that as part of life - there are always things that take up time. For Rajini, studies were the one thing she had apart from her mother and it was, in a way, a coping mechanism, something different on which she could focus. Clover said she worked harder because she saw it as something that could make her mother feel better. In comparison with adult carers, this is likely to be an outcome specific to young carers, given their age group.

"It was hard. It was really hard, I never had time to do homework. But it wasn't like I didn't want to go to school, my mum would say things like I'd get up and I'd be trying to get ready for school, she'd go "Oh, don't go into school today, stay off and we can sit and watch a film together" or "we can do this", or "I need help with that"." Pauline

Caregiving had also had a negative impact on work and career for some of the young adult carers, for example, finding it difficult to do a job properly because of the distraction.

"And I think, although that distracted me from a lot of other important things in terms of my career and I really didn't care about the things that were important. I ignored some other important things which were my career, my grades and things like that, I let them slip and I think, not to say my sister was at fault there, just to say I thought my sister was more important, I thought my family situation was more important." Tarun

Emotional impact and impact on physical and mental health

Other indicators of the stressful nature of caregiving are the emotional impact of the illness and its impact on the physical health and mental health of young carers. Part of the emotional impact of the illness is the sense of loss, described earlier under the primary stressors.

"*...it's not easy, the conflict of emotions that you go through, like you feel angry but you feel sad, you feel sad for the person going through it coz you understand they've got an illness, but it's hard because it's not just like they just get better coz they don't just get better, they're never get better, there's always episodes. And so you feel like you've conquered it you know, you feel like you've got over an episode and you can go back to building on a relationship which is with that person, and then it will happen again and you'll have to go through losing the person you care about and dealing with this nightmare of a person, and it's really conflicting emotions...*" *Antonia*

For one young carer, there was also an impact on physical health, leaving her exhausted and subject to migraines. Other interview participants expressed concerns about their own mental health. Huy was seeing a psychiatrist for what he called his OCD, another had harmed herself for some years and had been on antidepressants until she decided that she did not want to end up like her mother, and two mentioned their own depression.

"*That's what I mean, I got to a point where my migraines were seriously 3-4 times a week. I was getting serious migraines where I couldn't get out of bed properly and I was throwing up and I was just so worn out, I was exhausted, physically, mentally drained, I couldn't take it any more.*" *Pauline*

Arthur, who had been very involved with young carer groups and representing young carers, emphasised the psychological impact that could result from caregiving and

highlighted the importance of mental health awareness for young people looking after someone with a mental illness, in order to support them, especially since mental health problems (for both carer and person cared for) could be hidden.

Positive impact of caregiving

There were also feelings of satisfaction at being able to help others or support one's family. The most important of these was the strengthening effect on relationships. Clover and Tarun described the closer relationship they shared with the person they cared for as a result of the illness. Clover also highlighted the fact that the family's experience had made them stronger as a family in the end.

"*Being helpful, you get a feeling of accomplishment when helping them*" *FGD*

"*I think it makes you closer at the same time, it's like you lose parts of the relationship but you gain in other ways. Like I think she trusts me, I know a lot of mothers who don't trust their kids at all, especially teenage girls, they just, there's no trust there at all but my mum trusts me 100%, I know she does. So yeah, it's strong in those kind of aspects and things, so that's one good thing.*" *Clover*

The second positive aspect related to the ability of young carers to deal with people with whom others might feel uncomfortable, especially people with mental illnesses: Enid described it as being comfortable dealing with 'odd' people. She highlighted the understanding and insight into mental illness that young people who care for parents with mental illnesses develop, and another participant added to this by illustrating how she was better equipped by her experience to help people with mental illnesses.

The focus group participants categorised the following positive aspects of being a young carer in the second focusing exercise (Fig 4.2).

(i) Bond with person cared for or family, e.g. 'get to spend time with family', 'develop a stronger bond with the person you care for'

(ii) Impact on the person cared for, e.g. 'making someones[9] life easier'

[9] spelling as in the written notes

(iii) Support offered by young carer to family, e.g. ‘get to help my mum look after my dad so I know she doesnt[10] have to go through it alone’

(iv) What it does for young carer, e.g. ‘feel Respected’, ‘you get a feeling of accomplishment when helping them’

(v) Impact on young carer’s outlook on life, e.g. ‘it has enabled me 2B a more deeper person & 2 think deeply & making/managing every bit of time wisely’

(vi) Link with other people in a similar situation, e.g. ‘feel able to help others who are in The Same Situation’

There were also three responses that did not fit into the above categories – ‘can be easygoing being at home all the time’, ‘You have reassurances that if the situation is under your control things won't go wrong. If the loved one is in care (professional care) you feel powerless’ and ‘making changes for people’.

PROCESS OF LEARNING FOR YOUNG CARERS

Finally, these former young carers also described caregiving as a process of learning, wherein through experience and over time, they learnt about the illness: how it expressed itself and what they needed to do. Simon and Tarun described it as caring by trial and error. In decisions involving the person with the illness, sometimes the right decision could only be made after learning from experience.

“And I didn’t know anything about it, everything I saw from experience, I saw how my sister behaved as a result, what her triggers were, things like that. And they kind of, I adjusted my role accordingly, I changed my approach you know, as I learnt more and more about my sister, but I didn’t know anything, I was only 13, I didn’t know what the hell was going on.” Tarun

This process of learning finds its place in the stress process model as a mediator since young carers learn how to deal with the primary stressors and can begin to adapt to their caregiving role. This can be with the help of the mediating factors, but adaptation itself can be seen as a coping strategy - they had learned what to do and, as Tarun put it, “it becomes a way of life after a while”. Secondary stressors could be more difficult to

[10] spelling as in the written notes

learn how to deal with, and young carers described 'acceptance' and 'just getting on with it' (with regards to choice in caregiving) and 'have to keep going on at them' (with regards to lack of recognition of their expertise) as strategies. However, learning how to deal with the illness could reduce negative outcomes since the primary stressors are less likely to be seen as stressful. The important factors in this process are that they involve learning and changes over time.

"Yeah. I think I know I would deal with it again. If she got ill again, I would definitely find it better just 'cause I know what it's like, and sort of how it goes." Irene

THE STRESS PROCESS MODEL IN A YOUNG CARER CONTEXT

Fig 4.3: The adapted stress process model for young carers

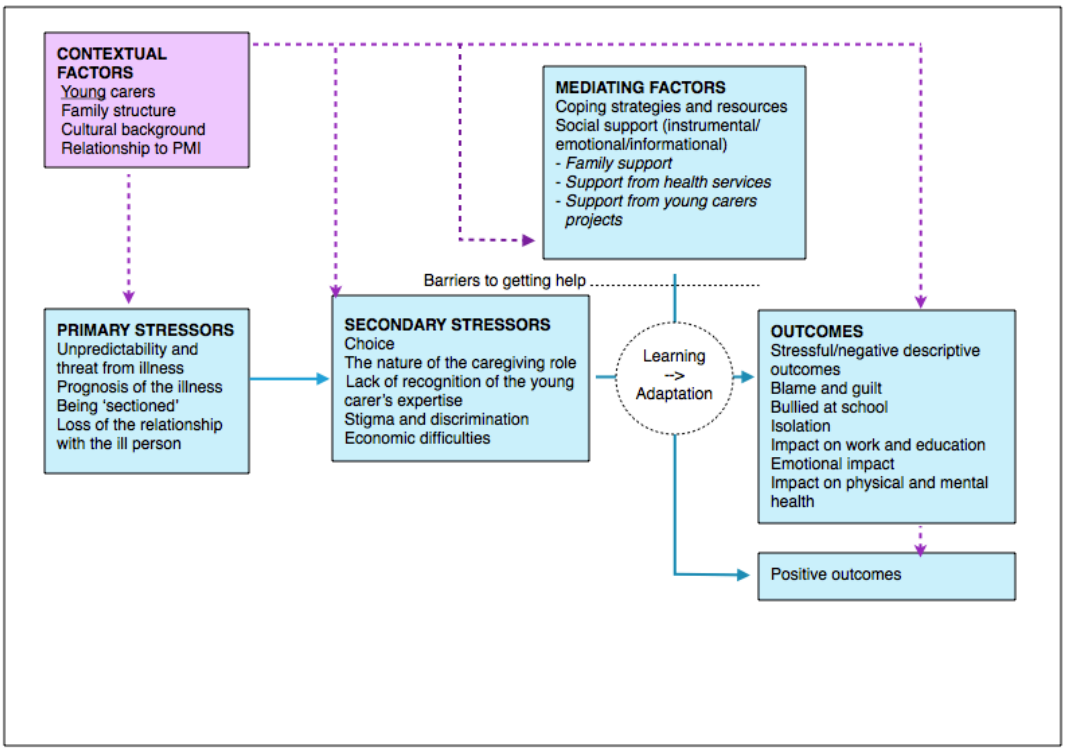


Figure 4.3. describes the stress process model as adapted to the young carer context, incorporating the factors described above. The interaction between factors in the model is further examined below.

What is the difference between supported and unsupported young carers in their outcomes?

The experiences of each participant were mapped to the model in Figure 4.3 in order to compare the stressors and the kinds of support received during caregiving (see Table 4.4). Irene was the only participant whose main caregiving role began after she turned 16. Two participants (Rajini and Huy) had no other family members as a resource, and three other participants (Irene, Enid, Antonia) initially had other family members available but later became sole caregivers. Five participants (Rajini, Naima, Tarun, Huy, and Abdul) came from a non-European minority ethnic background. Eight participants were caring for a parent with an SMI while the remainder were caring for a sibling.

All the participants had experienced at least one of the primary stressors and five participants (Irene, Rajini, Naima, Clover, Enid) had experienced all 4 primary stressors. Six participants (Mandy, Irene, Pauline, Arthur, Clover and Antonia) had experienced three out of five secondary stressors.

Some young carers described both positive and negative coping methods but the majority used positive coping strategies or increased resources. All the young carers had support from at least one source (family, health services, young carer project) and most had access to two kinds of social support (instrumental, informational or emotional support). Naima and Arthur had access to all three kinds of support, whereas Tarun, Huy, Beatrice, Clover and Enid only described access to instrumental support, although Huy was receiving support from a psychiatrist.

Most interview participants described at least one negative outcome of caregiving. Nine (Irene, Rajini, Naima, Tarun, Huy, Pauline, Beatrice, Clover and Antonia) described at least four out of seven negative outcomes. Abdul was the only participant who did not describe any negative outcomes for himself. Five participants (Mandy, Tarun, Pauline, Clover and Enid) were also able to describe positive outcomes.

Table 4.4 Mapping individual cases to the model

CONTEXTUAL FACTORS		PRIMARY STRESSORS		SECONDARY STRESSORS		MEDIATING FACTORS		OUTCOMES	
Young carers	*Exceptions:* Irene?	**Threat to self or others**	Mandy, Irene, Simon, Naima, Tarun, Huy, Beatrice, Clover, Abdul, Antonia	**Choice**	Irene, Rajini, Tarun, Huy, Pauline, Arthur (initially), Clover, Enid, Antonia	**Coping strategies and resources**	*Reduced coping resources or negative strategies:* Irene, Simon, Rajini, Naima, Tarun, Huy, Pauline, Arthur, Antonia	**Stressful/ negative descriptive outcomes**	Mandy, Irene, Simon, Rajini, Naima, Tarun, Huy, Pauline, Beatrice, Arthur, Clover, Enid, Antonia
							Increased coping resources or positive strategies: Mandy, Irene, Rajini, Naima, Tarun, Huy, Pauline, Beatrice, Clover, Enid, Abdul		
Family structure	*Available* Mandy, Simon, Naima, Tarun, Pauline, Beatrice, Arthur, Clover, Abdul,	**Prognosis of the illness**	Irene, Rajini, Naima, Beatrice, Clover, Enid, Antonia	**The nature of the caregiving role**	Mandy, Irene, Simon, Pauline, Beatrice, Arthur, Clover	**Social support**	**(instrumental/emotional/ informational)**	**Blame and guilt**	Mandy, Irene, Rajini, Naima, Tarun, Huy, Pauline, Beatrice, Clover, Antonia
	Not available Irene (later), Rajini, Huy, Enid (later), Antonia (later)								
Cultural background	Rajini, Naima, Tarun, Huy, Abdul, Antonia (mother)	**Unpredictable nature of the illness**	Mandy, Irene, Simon, Rajini, Naima, Tarun, Pauline, Arthur, Clover, Enid, Abdul	**Lack of recognition of young carer's expertise and inclusion in treatment**	Mandy, Irene, Simon, Tarun, Pauline, Arthur, Clover, Enid, Antonia	***Family support***	Mandy, Irene, Simon, Rajini , Naima, Tarun, Huy , Pauline, Beatrice, Arthur, Clover, Enid, Abdul, Antonia	**Bullied at school**	Rajini, Pauline's brother, Beatrice (would have been), Arthur
Relationship to PMI	*Parents* Irene, Rajini, Huy, Pauline, Arthur, Clover, Enid, Antonia	**Being 'sectioned'**	Mandy, Tarun, Huy, Arthur, Enid, Abdul, Antonia	**Stigma and discrimination**	Mandy, Irene, Naima, Pauline, Beatrice, Arthur, Clover, Abdul, Antonia	***Support from health services***	Rajini, Naima, Huy, Pauline, Beatrice, Arthur, Enid, Abdul, Antonia	**Isolation**	Rajini, Antonia
	Siblings Mandy, Simon, Naima, Tarun, Beatrice, Abdul								
						Support from young carers projects	Irene, Simon, Rajini, Naima, Tarun, Huy, Pauline, Arthur	**Impact on work and education**	Mandy, Irene, Naima, Tarun, Huy, Pauline, Beatrice, Arthur, Clover, Enid
								Emotional impact	Mandy, Irene, Naima, Tarun, Pauline, Beatrice, Clover, Enid, Antonia
								Impact on physical and mental health	Irene, Huy, Pauline, Beatrice, Clover
								Positive outcomes	Mandy, Tarun, Pauline, Clover, Enid

Mapping the cases to the model indicates that the stress process is a complex one, influenced by a number of concurrent factors. Furthermore, while this study data showed only some changes over time, the stress process model can be used as a framework to study quantitative changes in outcome over time; for example, a young carer might not receive any support initially but later find access to services and support, and this could change his/her outcomes.

Some examples of the application of the framework are given below.

- While Enid found her caregiving experience difficult and upsetting, she felt that she was less distressed at becoming her mother's sole carer after her sister moved away. This was partly due to the instrumental support she had from her extended family and her school, partly due to learning from her sister, and partly due to her own active coping strategy of seeking help. Even though caregiving had an impact on her education, the support provided by her school was helpful in reducing this.

- Rajini actually received emotional support outside the young carer project she attended, through a social worker who acted as a confidante. Even though her relationship with her mother was a source of support, it was inadequate since that was the only source of support. While the relationship with the ill person can be a source of support, it is important that other sources are also available for the young carer.

- Naima described negative outcomes that predated her access to all three kinds of support. The emotional and instrumental support she received from other family members, friends and the young carer project was especially helpful in reducing negative outcomes and enabling her to lead her own life. This substantiates the role that social support plays in mediating negative outcomes for young carers.

- Abdul is an example where the primary stressors are present but as the youngest child, he had little caregiving responsibility and a lot of family support, which appears to have mediated the impact of the stressors.

- Pauline's narrative illustrates the importance of emotional support.

"But it is just so terrifying when you have to deal with all this stuff and you don't know what to do and you have no one to help and you just have to get on with it."

Table 4.5 Comparing participants with and without support from young carer projects

CONTEXTUAL FACTORS		PRIMARY STRESSORS		SECONDARY STRESSORS		MEDIATING FACTORS		OUTCOMES	
Young carers	*Exceptions:* **Irene?**	**Unpredictability and threat arising from the illness**	Mandy, **Irene**, **Simon**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, **Arthur**, Beatrice, Clover, Enid, Abdul, Antonia	**Choice**	**Irene**, **Rajini**, **Tarun**, **Huy**, **Pauline**, **Arthur** (initially), Clover, Enid, Antonia	**Coping strategies and resources**	*Reduced coping resources or negative strategies:* **Irene**, **Simon**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, **Arthur**, Antonia	**Stressful/ negative descriptive outcomes**	Mandy, **Irene**, **Simon**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, Beatrice, **Arthur**, Clover, Enid, Antonia
							Increased coping resources or positive strategies: Mandy, **Irene**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, Beatrice, Clover, Enid, Abdul		
Family structure	*Available* Mandy, **Simon**, **Naima**, **Tarun**, **Pauline**, Beatrice, **Arthur**, Clover, Abdul,	**Prognosis of the illness**	**Irene**, **Rajini**, **Naima**, Beatrice, Clover, Enid, Antonia	**The nature of the caregiving role**	Mandy, **Irene**, **Simon**, **Pauline**, Beatrice, **Arthur**, Clover	**Social support**	**(instrumental/emotional/ informational)**	**Blame and guilt**	Mandy, **Irene**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, Beatrice, Clover, Antonia
	Not available **Irene** (later), **Rajini**, **Huy**, Enid (later), Antonia (later)								
Cultural background	Rajini, **Naima**, **Tarun**, **Huy**, Abdul, Antonia (mother)	**Being 'sectioned'**	Mandy, **Irene**, **Simon**, **Rajini**, **Naima**, **Tarun**, **Pauline**, **Arthur**, Clover, Enid, Abdul	**Lack of recognition of young carer's expertise and inclusion in treatment**	Mandy, **Irene**, **Simon**, **Tarun**, **Pauline**, **Arthur**, Clover, Enid, Antonia	***Family support***	Mandy, **Irene**, **Simon**, **Rajini** , **Naima**, **Tarun**, **Huy**, **Pauline**, Beatrice, **Arthur**, Clover, Enid, Abdul, Antonia	**Bullied at school**	**Rajini**, **Pauline**'s brother, Beatrice (would have been), Arthur
Relationship to PMI	*Parents* **Irene**, **Rajini**, **Huy**, **Pauline**, **Arthur**, Clover, Enid, Antonia	**Loss of relationship with the ill person**	Mandy, **Irene**, **Rajini**, **Naima**, **Tarun**, Beatrice, Clover, Enid, Antonia	**Stigma and discrimination**	Mandy, **Irene**, **Naima**, **Pauline**, Beatrice, **Arthur**, Clover, Abdul, Antonia	***Support from health services***	**Rajini**, **Naima**, **Huy**, **Pauline**, Beatrice, **Arthur**, Enid, Abdul, Antonia	**Isolation**	**Rajini**, Antonia
	Siblings Mandy, **Simon**, **Naima**, **Tarun**, Beatrice, Abdul								
						Support from young carers projects	**Irene**, **Simon**, **Rajini**, **Naima**, **Tarun**, **Huy**, **Pauline**, **Arthur**	**Impact on work and education**	Mandy, **Irene**, **Naima**, **Tarun**, **Huy**, **Pauline**, Beatrice, **Arthur**, Clover, Enid
								Emotional impact	**Naima**,**Tarun**, Clover, Antonia
								Impact on physical and mental health	**Irene**, **Huy**, **Pauline**, Beatrice, Clover
								Positive outcomes	Mandy, **Tarun**, **Pauline**, Clover, Enid

"I had to get away from that. I couldn't take it any more. I got to a point at about, what, it was only last year, it was only, I think it was March or April last year, I broke, I completely snapped... ...I had to get away from her I couldn't physically deal with her anymore, I was just beyond… I just didn't know what to do anymore. The only way I could cope with my mum was to self harm, which I started doing when I was 16. She was no help, no support, no anything. She doesn't, she can't help anyone else, she just wants. D'you know what I mean? She never gives, she never helps, she's a nightmare. And I got to a point where I couldn't physically take it anymore, and my dad picked me up and I went to stay with him."

"It doesn't matter how old you are, you need someone to be able to just get it off your chest, even if it's someone that doesn't know what they are talking about."

*"If it wasn't for his [her partner's] support I think I probably would have gone mad. But I've built up a network on our own, it's only having what you've got isn't it and without my brother and without L**** and my dad it would be mad. They have been great."*

"It would just be nice if they had some kind of, even down to social workers, if when someone in a situation like that where you don't have another adult around, if you're given that kind of, just a number, somewhere where you can go to for advice and help." Pauline

Comparing young carers with and without support from young carer projects

One of the strengths of the study sample is the inclusion of young carers who were not supported by young carer projects as well as those who did receive such support. Table 4.5 highlights the eight participants who were in contact with a young carer project (or in the case of Tarun and Irene, a carers service), marked in red. From this table it can be seen that these participants faced similar stressors to the others and there was little difference in their contextual factors or in the kinds of outcomes they reported. While it was clear that the support they received from young carer projects was felt to be helpful and had some impact on outcomes, it does not appear to be sufficient in itself to provide all three types of support young carers felt they needed. For example, Tarun needed informational and emotional support which he was not able to access through the carers project. Rajini had further emotional and informational support needs, in spite of being

in touch with a young carer project. On the other hand, Arthur had received all three kinds of support from his young carer project and a social worker, and his outcomes improved after he began receiving support.

"Yeah I really enjoyed it, it was the sort of thing where, especially between, so I benefitted most from it between 14 and 16 I think, having that sort of regular chance to have a break, meet other young carers who have experienced similar issues, also having someone there who could come in to school if things were bad, who could help trying to explain to teachers and make awareness, was something really beneficial." Arthur

The level of support received may not be adequate or, in the case of mental health services particularly, consistent. Often a young carer would have support from mental health services, but at the same time express the need for services to recognise and listen to their point of view, and to provide information about the patient and the illness.

Mapping the model reflexively to the researcher's own experience

My father developed severe clinical depression when I was a teenager. His behaviour, mainly emotional outbursts, was noticeable long before my mother realised something was wrong and insisted that he seek help. In the Indian context, public information about mental illness is limited and there is a lot of stigma attached. While he was able to access help first from a neurologist and then from a very good psychiatrist, it took my father a while to accept that he could have depression. We come from a very close knit family and the support of both my parents and their willingness to work through this was a key factor in reducing negative outcomes for the family. Our dependence on our faith for emotional support and the support that my parents received from their friends was also crucial. Our large social network meant that my parents could call on the support of family and friends in difficult situations. It was not until recently, however, that my parents began to tell people what the problem really was and even now, there are not many people who know. It is not something that can be discussed openly in Indian society.

Dealing with my father's emotional outbursts as a child was stressful, because I never knew what would trigger them. While my mother tried to explain to us that he was unwell and why, it was still very hard to understand why he would get so angry, so sad, and so different. The only impact was emotional - thanks to the support and efforts of

both parents. There were even positive outcomes. It has certainly made us stronger as a family, it has increased my interest in mental health, it has directly led to this thesis, and it has strengthened our faith and our social networks. It has also taught me the importance of being careful of my own mental health. Mapping the model reflexively to the researcher's experience explores the applicability of the model from the "insider's" perspective. Given the difference in the cultural context, it is helpful to know that the main factors remain the same. The main difference was the absence of religious faith as a source of support in the model described above (Figure 4.3).

USING THE STRESS PROCESS MODEL TO IDENTIFY SUPPORT NEEDS OF YOUNG CARERS

The relevance of adapting the stress model to a young carer context lies in its implications for supporting young carers. If particular coping strategies and the availability of social support are mediating factors, then it could be hypothesised that increasing these will reduce negative outcomes.

The support needs identified by young carers in the study can be categorised according to the three commonly recognized types of social support.

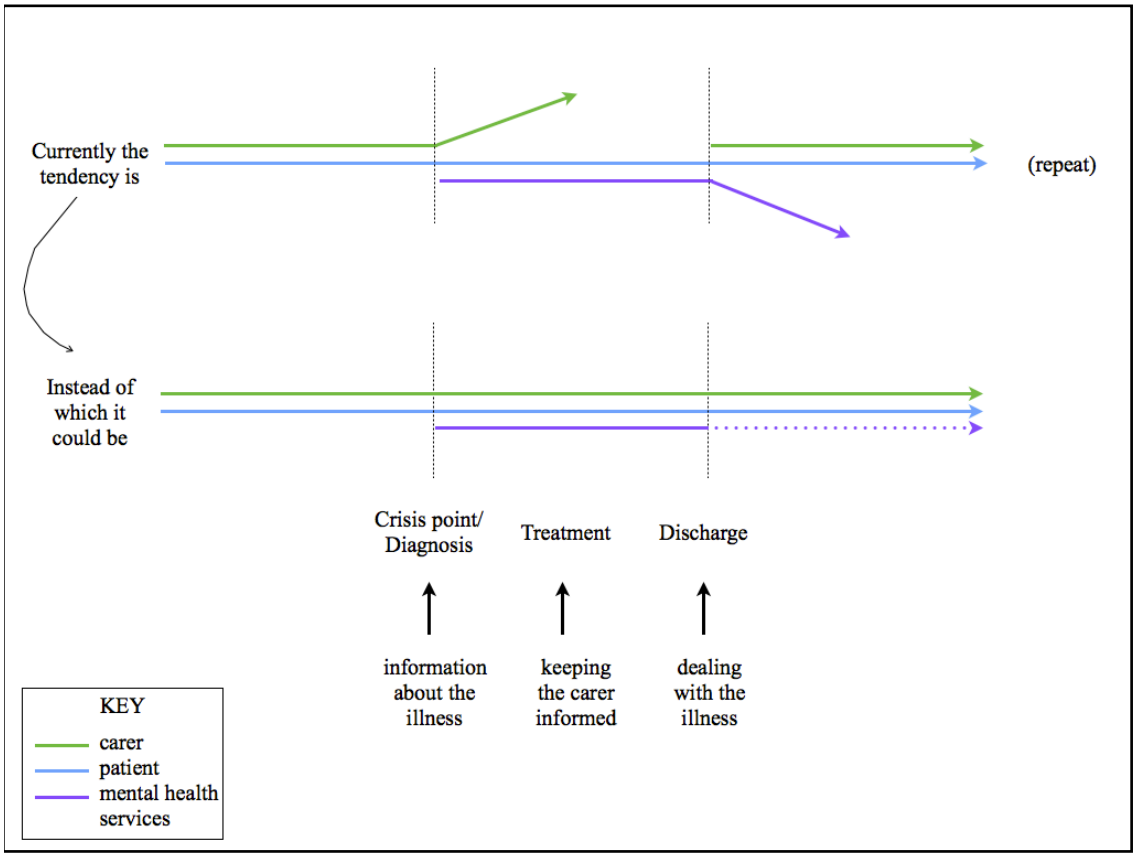
Informational support

Participants emphasised the need for information about the illness and services available, advice on how they might deal with the illness, and having access to a key contact in the mental health service who could explain what was going on. It was suggested that this could be provided by mental health services, a new independent service, or a young carer project; however, given the nature of the information required, it is more likely that it would need to be provided by mental health services. The categories of information needed were linked to the stages in the illness and treatment of the family member, and the model below sets out participants' suggestions for how these needs could be addressed (see Figure 4.4).

For some young carers, a loved one developed symptoms earlier (e.g. Mandy's brother), but it was only when the situation reached a crisis point that a mental health problem was diagnosed and treatment began. Usually at this point the young carer was not

involved as the person underwent a period of treatment, either at home or in hospital (e.g. Clover, Tarun). With parents, the illness might be known, but there were still points of crisis and periods of treatment (e.g. Arthur, Antonia). If the person had been hospitalised, they might return to the care of their families on discharge (e.g. Beatrice, Enid).

Fig. 4.4: Providing young carers with the information they need at different stages of the illness



The model indicates the need for information at three different stages. When a loved one is diagnosed and treatment begins, young carers wanted tailored information about the illness, its causes, what could be expected, what hospitalisation can achieve, and to be able to discuss their concerns. During treatment, the young carer needs to be kept informed about what is happening to the patient. On discharge, the young carer needs to know how to deal with the illness: what to expect, who to call in an emergency, how to help the person. It could also include guidance for young carers looking after people with episodic illnesses. If treatment takes place while the person is at home, then stages

2 and 3 could be combined, providing young carers with the information they need to look after the person and keeping them informed about treatment.

"Or just to have a phone number to ring coz I wasn't given anything like that, the GP never once spoke to me about, obviously coz of confidentiality so, yeah I mean I didn't know if anything went wrong, like when it did go wrong, I didn't know who to ring, I didn't know what to do and that was the scariest part because when she took the tablets I had absolutely no idea what to do." Clover

Recognition of young carers' role and experience, listening to them and the need for involvement of the whole family are overarching themes in this model. Providing information at key stages as outlined above could enable professionals and carers to work together in support of the patient. It also requires information to be tailored to the individual experience.

"I think in terms of a mental illness maybe people have to look at it differently and think that it's a thing that affects whole families." Mandy

Instrumental support

The need for respite from caregiving and to have time for themselves was the main form of instrumental support identified by young carers.

Respite

It was suggested that this could be provided by somebody coming in to the home to look after the ill person. While Clover did not seek the opportunity of going away, as she would continue to worry about her mother, having somebody come in would have helped. Pauline was against carers coming in to support her, for financial reasons and because she found the concept "scary", and felt that professional carers would not know exactly how her mother liked things to be done. Focus group participants discussed the possibility of respite houses or holiday homes where both the young carer and the person cared for could take a break, with activities provided for families to come together, but also with the opportunity for the carers to do things by themselves, knowing that their loved ones were being looked after. Several participants in the focus group supported the suggestion that respite could provide the opportunity for the young carer and the ill person to spend time together in a more positive environment.

"I think one of the things I agree with you is the respite issue. I know that, probably got it wrong, I know when you've got respite, they take carers out, to help them get respite from the role, so here's a break, you don't have to care during this point, but then when you come back, you get to that environment again, that's your norm. But when you take the carer and the person you're caring for in a new environment, that gives you an opportunity to create a new norm, so you can say that it doesn't always have to be about the bad stuff, the mental health, you harming yourself, we can have a good experience in a different environment. " Focus group participant

Nominal group participants emphasised the difference between mental illness and physical illness since it was unlikely that somebody else could take their place in providing the type of emotional support they did. This meant that shorter breaks were more likely to be helpful. While enabling families to have a holiday together could be especially helpful for financially straitened families, this would be difficult to implement if the ill person was either unwilling or still very ill, requiring constant attention from medical professionals. Finally, one former young carer suggested that respite could also be provided by having a suitable space in hospitals where families could spend time together in a positive environment.

Emotional support

Meeting other young carers could also be a source of emotional support. Participants also identified the importance of having a confidante.

Meeting other people in a similar situation

Young Carer Projects already provide this type of opportunity and participants agreed that it helps to know that there are other people in a similar situation and that this can increase their understanding of their own situation and help them to feel supported. Some participants who had attended young carer projects had not found that they were able to talk about their experiences. It was suggested that projects could encourage young carers to share their experiences by providing activities during which they can open up to each other. This could be provided as support groups where young carers could meet other families or other young carers to discuss the changes in their lives due to mental illness and find out more. Participants suggested that such groups could help the young carer with their anger and to find better ways to cope with the situation.

Mandy suggested that groups of people with illnesses and their carers could go out socially, since social support could have a positive effect, but other participants cautioned that it would depend on the circumstances and current health state of the ill person.

"And also no one was talking about the fact that they were a young carer, it was as if that didn't exist at all so yeah, I mean I would have liked to have been able to say 'Look, I don't speak to any one because I'm a young carer', I would have liked to speak to someone, just sort of shared my feelings with them or found someone similar to me but there didn't seem to be anyone at all..." Rajini

"Yeah they've [Young Carer Project] been good, it's a nice place to go and talk with the rest of the young carers, not so much now 'cause I don't really have time but when I was younger it helped because they do activity groups and days to the theatre or meals out, so it was just a chance to socialise but also vent your frustration with, and also it was a good opportunity to see that my situation is not the worst because some of the stories you hear are a million times worse than you are in, it put things into perspective." Naima

The nominal group felt that meeting other young people in a similar situation was helpful because of the accompanying, often unspoken sense of understanding - young carers did not have to explain their situations - and because it helped young carers feel less isolated. While there was more understanding if the other person was also caring for somebody with a mental illness, it was still helpful to meet young carers looking after people with other kinds of illnesses since the underlying sense of responsibility was similar. Meeting young carers who are slightly older, in particular, was thought to be helpful because it could give a feeling of hope. A suggestion made in the interviews for groups of patients and carers to meet and undertake some sort of social activity was once again felt to be dependent on the people involved and their situations.

Somebody to talk to

Young carers needed to be able to talk to someone who understood their experiences, whom they could contact for information, advice and support and for help with big decisions, who could help them get access to information. As Tarun suggested, this person might act as an advocate with services. Participants found it helpful to know that

there was someone who cared about them, who kept in touch by phone or email and who would check on their welfare. They believed this would reduce the sense of isolation. Five participants had received formal counselling; some had found the opportunity to talk about their experiences helpful. Rajini had not found either art therapy or counselling to be helpful at the time, while Antonia found it more appropriate when she was a little older.

The most appropriate confidante was thought to be an adult outside the family who could offer a neutral perspective on the situation. While having somebody in school to talk to could be helpful, Arthur cautioned against counselling being provided by a teacher, since concerns about confidentiality could prevent some young people from accessing the service. It could also be helpful if this person had some understanding of the cultural background of young carers from minority ethnic groups.

"Yeah, I mean you are scared of all this stuff and there's no one to talk to, there's no one to say yes, this is normal, no, it's not normal or, don't worry, they can't take you away, or just that bit of support just to say it's ok, have a moan, have a cry, whatever. There was nothing, honestly nothing and it was hard." Pauline

"...and also to have like, I don't know, just someone to talk to who maybe was older and didn't have any kind of relationship with the family or friendship with the family or anything like that, who kind of understood what was going on would have been good." Antonia

The nominal group identified the need for consistency in having access to the same person so that the young carer could build up rapport and trust with someone who knew their circumstances. Furthermore, if the relationship was sustained, parents would feel that they could trust the person with their child. It was suggested that some might find it helpful to have support from a non-teaching staff member in school while others might prefer the informality of talking to a young carer project worker.

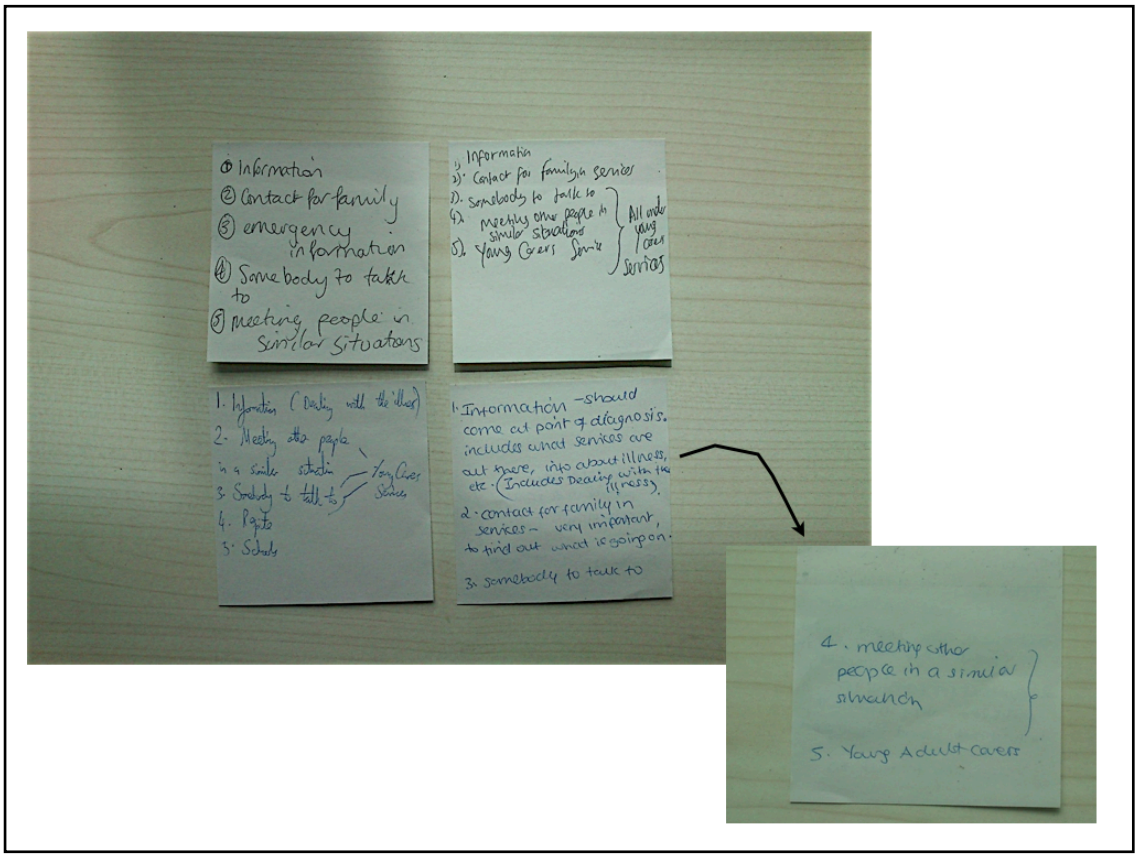
Sources of support

The concept of needing different kinds of social support was supported in the nominal group, who rated the kinds of support listed previously (see Figure 4.5). Information,

somebody to talk to and meeting other young carers were the three that were common across participants.

"...so actually, if you've got all those sort of tools to equip you to be able to deal with that, is something I think would be really useful, 'cause it's not going to reduce the amount of caring you do necessarily, or it's not going to miraculously make your parent better but what it'll do is mitigate the effect it has on the carer I think, because they've got those sort of support mechanisms in place..." Nominal group

Fig. 4.5. Ratings of support types by the nominal group



Participants also confirmed the potential for support to be provided through other means, as seen in other literature; they highlighted the support that could be provided by schools, the need for young adult services, for a designated professional or single contact in healthcare services, and the responsibility of local authorities in strategic planning and coordination between services. Schools, particularly, could be a way to widen access to support for young carers.

Additional factors to be considered

Finally, data from participants indicated that support that is provided for young carers will have to take into account the contextual factors described in the model - the age of the young carer (whether child or young adult in terms of the different issues involved, the specific age level in terms of ability to comprehend information provided), the family structure, the cultural background and the relationship to the person they look after. For example, participants highlighted the need for more awareness and understanding of mental illness in communities and individuals from minority ethnic groups. This could be facilitated by providing a culturally sensitive explanation of mental illness, with information on how to live with it and support recovery, by somebody who knows the culture in question and its perceptions of mental illness and who has experience of working with mental illness.

Young adult carers in the transitional stage between 16-25 years will continue to require support in planning for their future, and to enable them to feel that they can move on in their lives. A service for young adult carers would need to be tailored to providing guidance and sign-posting to other relevant services, rather than providing respite.

"I think we've covered all of it, as I said one key thing I am really keen on is the transitional support because there are so many young carers out there who potentially would want to go on to university for example, or would want to move away but feel sort of tied down, coz like I said with me it's like, well how will my mum cope once I go away, and I think that is really important in terms of making sure there is that targeted provision to making sure that they can actually have, making the choices they want to make rather than settle for what they feel like they have to." Arthur

Support for young carers and families, both within and outside mental health services, needs to be proactive in engaging with young carers and families and looking for ways to support them before crises arise. Even when young carers had received support, earlier recognition by doctors and teachers might have expedited the links to support.

Participants' accounts indicated a need for interventions to address early signs of stress and depression in young carers to help them remain psychologically healthy while providing care. The need for young carers to be aware of mental health problems and how to cope with these were identified as important, as was the ability to recognise

one's own need for help. This requires greater public awareness of mental illness, less stigma and being able to talk about mental illness openly.

Barriers and facilitators to providing help through services

The interviews with support workers were another source of data, triangulated with the interviews and focus group discussion with young people. They augmented the data on supporting young carers of people with SMI and identified key barriers and facilitators to providing this support.

Support workers from young carer projects indicated that the three main support needs identified by the nominal group (information, somebody to talk to and meeting other young carers) were being met in their projects. However, the level of involvement of families depended on judgements made by individual projects and the resources available. Support workers' responses to the interventions suggested by participants varied from those who felt there was nothing new to those who felt it had given them a lot to think about. Support workers from young carer projects identified informational support, in terms of how to deal with the illness and a contact for the family within mental health services, as the gaps in their service, and felt that they belonged to the remit of mental health services and required their partnership to facilitate provision. Support workers from one young carer project identified instrumental support, such as parenting support and advocacy, as interventions provided by the project that were missing from the interventions suggested by study participants. They felt this might have been because the impact of those interventions were less visible to young carers.

Support workers identified barriers to providing support and some aspects that facilitated support. The support worker from the adult carer service identified the gap as the need for working with the whole family. She also felt that different carer services could do more to work in partnership, particularly around the transition of young carers after the age of 18, but she identified the competition between charities for limited funding as a barrier to this. The remit of the support workers from carer and young carer projects tended to be based on their funding.

The support worker from the CMHT identified gaps in the support provided to young carers, including a need for the service to be better connected to the community and to community services, and a need for training of care coordinators to be oriented towards

a whole family approach. Barriers to providing support for young carers included the timings of the CMHT (9-5), which meant that staff did not see children very often, the client-focused, illness-focused nature of the service and the risk of an increased workload that made working with the whole family difficult, plus a system that recognised only one carer at a time. However, support for young carers could be improved if a detailed record were kept of the children connected to the service. Support could be further facilitated by training and emphasising a whole family approach. Having a clear definition of who a young carer is could also facilitate the support of young carers by care coordinators.

"I think, understandably from their point of view, they would say that that's not their role. Their priority, their client, is the parent, their client's not the young carer so I suppose it's whether people want to go above and beyond the role really, and kind of engage with the young person, but they are under a lot of pressure, understandably so they might not have that 5 or 10 minutes to sit down with the young carer and have a conversation about why mum's just come out of hospital or what the prognosis for the future is." SW06

A lack of awareness about available services, a lack of recognition of the role played by young carers, the stigma associated with mental illness, and a lack of communication between services, can all contribute to preventing young carers from getting the help they need. Referrals from the CMHT to young carer projects were not always taken up. Young carers might not be identified as needing support if there is more than one carer in a family. One support worker wondered whether belonging to a young carer project could itself be stigmatising.

While collaboration with other projects could facilitate the support of young carers, the uniqueness of young carer projects in terms of the targeted population and services provided could hinder the joint provision of services. Limited resources, primarily funding, were identified as the main barrier to supporting more young carers, providing an optimum service or working with the whole family.

Support workers from one project identified working with schools and young adult carers as the most difficult to implement of the suggested interventions because of limited resources. It would require a dedicated drive towards building links with schools

and other organisations. Supporting young adult carers was difficult for other reasons as well: identifying them and their specific support needs, young carers not knowing where to go once they turn 18, and the geographical mobility of that population. The lack of a strategic joint approach hindered a smooth transition from a young carers service to an adult one.

"...but I think one of the other things is they're a very moving population aren't they? So I might set up a group for them and then somebody goes to university, somebody gets a job up north or they find a boyfriend or they go travelling, so just actually how do you provide services for young people who naturally are going on lots of different pathways and that again, there's a transition issue there isn't there, so if they were going to university or a job in another area, how do you make sure that that support is provided elsewhere?" SW02

Many of these have been identified previously as barriers to collaborative service provision and a whole family approach (SCIE, 2012). However, limited resources do not have to be an insurmountable barrier; preventive or early interventions, mentoring schemes (i.e. peer support with supervision for adult carers), partnership working and referrals to appropriate services, were all identified as ways of working with limited resources. One young carer project had commissioned some research to find a solution to their long waiting list; they limited the number of young carers they worked with and the length of time they were with the project. Allowing more small projects to come together under a single "umbrella' organisation was suggested as a means of creating a more strategic approach to young carers service provision. Where there was a lack of services for young adult carers, one young carer project had endeavoured to remain in contact with former attendees and encouraged them to volunteer with the project. Services for young adult carers could be provided alongside those for younger or older carers, using existing infrastructure, but they would need to be adapted to the age group.

Who needs support?

The likelihood of negative outcomes depends on a complex network of related factors. The relationship between young carers' responsibilities, the presence or absence of family support, the impact of caregiving and whether or not a young carer was living with the ill family member were mapped for a selection of participants (50%,

consecutively selected). This showed that living with a family member with a mental illness, the impact from it and having a caregiving role are independent and not necessarily concurrent. A young carer can have caregiving responsibilities (e.g. Tarun) and be affected by the experience (e.g. Irene), even when they are not living with the ill person. On the other hand, a young carer can also live with the ill person without perceiving themselves to be affected, as was the case for Irene when her mother went through a period of recovery. Furthermore, living with the ill person could have an impact even when the young person did not have a caregiving role (e.g. Mandy, Huy). Abdul is an example of a young carer who had limited caregiving responsibility and seemed to have been minimally impacted by the experience, probably due to the number of other family carers around him. It also showed that there can still be a perceived need for support after the young carer's role has been reduced, or when they are no longer living with the person with the illness.

This raises questions about the difference between a young carer and somebody living with a family member with a severe mental illness. While the experience can be more difficult with caregiving responsibilities, particularly as a sole carer, there can be an impact regardless of whether or not the young person has a specific caregiving role. Moreover, even those young carers with family support, who were not the primary carers, had been affected by the illness.

CHAPTER 5: DISCUSSION

This chapter discusses the findings from the qualitative study described in the previous chapter, as well as from the systematic review. The findings are placed in the context of existing young carer and adult carer literature. The implications of the model derived from the data analysis in terms of guiding interventions for this population are discussed. Finally, the strengths and limitations of this study are considered.

Summary of key findings

One of the key strengths of the study sample is the ability to compare the experiences of those who were supported by young carer projects and those who were not. This was done qualitatively using the stress process model as a theoretical framework to guide the data analysis. It identified little difference in perceived outcomes for both groups. The findings suggest that young carer projects do not provide all the different kinds of support required (see below) and have a limited impact on outcomes.

The inclusion of social support as a theoretical factor in the stress process model is important because it indicates the distinctions between the kinds of support needs of young carers. The results suggest that all three kinds of social support (informational, instrumental and emotional support) seemed to be required to fully enable a person to cope.

While the need for information of various kinds is familiar from the literature (Chen and Greenberg, 2004), this study clarifies the stages at which particular types of information are required.

It is known that children and young siblings of people with mental illness are at risk of negative outcomes and that care giving can have an impact, but the results seem to indicate that living together, having caregiving responsibilities and impact do not necessarily occur concurrently. Such children and young people may still need support from services when they have no specific care giving responsibilities or when they are not living with the person with SMI. This supports the argument for a whole family approach wherein the needs of all family members are taken into consideration.

Most importantly, this study provides a model for understanding the experience of young carers looking after someone with SMI and a framework within which support can be planned. For example, somebody who has family support at home is likely to be receiving the emotional support they need, and may only require instrumental or informational support from external sources. On the other hand, a sole carer for a parent is likely to need more emotional support which may be provided through a confidante at a young carer project.

The stress process model in young carers of people with SMI

Contextual factors

The adapted model has confirmed the necessity of taking into consideration the age of the young carer in determining support needs. Those approaching the transition to young adulthood will be facing decisions about their future lives, such as work, training or higher education and relationships, which may be inextricably linked to their ability to continue care giving. This study has confirmed other research (Becker and Becker, 2008) indicating that the issues specific to young adult caregivers (18-24 years) are different from those faced by younger carers. Those approaching adulthood may be facing increased expectations and restrictions from caregiving, while needing information about education and careers, and services available after they turn 18 (Becker and Becker, 2008). On the other hand, the current study found that older young carers are also likely to have more expertise in caregiving through a process of learning, and feel more able to cope. Similarly, those who are very young may be less likely to be able to understand what is going on and require age-appropriate information. A younger child may not be able to undertake particular kinds of tasks (Roberts et al., 2008, citing Dearden & Becker, 2004). A study of adult siblings of people with serious mental illness also identified the age of the caregiver to be associated with increased stigma and fears for own or patient safety (Greenberg et al., 1997).

This research provides further insight into the influence of the relationship of the carer to the person with the mental illness. Newman (2002) considered caregiving for parents and siblings in his paper and identified the potential for positive outcomes in both cases. However, there is little literature that compares the experience of caring for a parent

with caring for a sibling with a mental illness. By including both kinds of relationships, we were able to compare the experiences and identify the higher level of family support available (usually from parents) when caring for a sibling, and the difference in the impact, particularly in the loss of the relationship with the ill person. Dearden and Becker (2004) found that young carers caring for siblings are more likely to belong to households with two parents, whereas those caring for mothers are more likely to be from lone parent households.

Primary stressors

The primary stressors identified by former young carers in this study - unpredictable behaviour, threat to self or others, concerns about the prognosis, being 'sectioned' and loss of the relationship - are all familiar concepts from the literature on adult carers of people with SMI. Szmukler and colleagues (1996) identified difficult behaviours and negative symptoms as predictors of carer burden. In other studies, the level of psychiatric symptoms exhibited by a person with mental illness has been found to be associated with subjective burden (Greenberg et al., 1997), worry and stigma (Baronet, 1999) in caregivers. Zegwaard and others (2011) in their review identified changes in behaviour and mood, as well as the frequency and severity of problematic behaviour, to be important stressors for caregivers of older persons with SMI. Negative symptoms and passive behaviour were more of a concern because they were seen as a lack of motivation and cooperation on the part of the ill person. In contrast, Möller-Leimkühler and Wiesheu (2012) posited that illness-related patient characteristics were less related to perceptions of burden amongst caregivers of chronic mental illness than family interactions and social support.

Similar to the accounts of the former young carers in the present research, a qualitative study of family caregivers' experiences of involuntary psychiatric hospital admissions identified relief and conflicting emotions in response to hospital admission as one of the major themes (Jankovic et al., 2011). Frustration with the delay in getting help, the feeling of increased burden from services and difficulties with confidentiality were reported by participants in both studies. Loss, in terms of grief, has previously been identified as part of the emotional consequences of caregiving for older people with psychiatric problems as a stressor (Zegwaard et al., 2011).

Given that the primary stressors of caregiving are specific to the illness under care, the stress process model indicates that the support needs of young carers of family members with severe mental illness should be considered in their own right.

Secondary stressors

The concerns of this population which are considered to be secondary stressors have been identified previously in research on young and adult carers. Just as adults caring for family members with severe mental illness do not feel that they have a choice in caregiving (Kuipers, 1992), Aldridge (2008) highlighted the lack of choice that children often have in the onset, type and extent of caregiving responsibilities. She attributed this to a lack of adequate support and recognition of their contribution. Children need to have their caregiving role recognised and to be included 'on their own terms'. However, this recognition of their role should neither be placing too much responsibility on them, nor should it prevent them from being able to choose to care or not. Aldridge and Becker (2003) have also pointed out that the role can fluctuate as the parent's condition changes.

Seeking help can be a challenging process for young carers. Children have been able to describe their awareness of stigmatizing attitudes and this can make it difficult for them to reveal their experiences or to seek support (Cogan et al., 2005). Typically, they may try to find a balance between avoiding stigmatizing situations and seeking to be seen as 'normal' (Fjone et al., 2009). In addition, financial difficulties as a secondary stressor is likely, given the two-way relationship between parental mental health problems and financial difficulties with employment, benefits, debt and housing (Family Action, 2011, Aldridge, 2008).

Mediators

The finding that coping strategies and resources and social support have the potential to mediate negative outcomes is supported by earlier literature on adult and young caregivers. The association between maladaptive coping strategies, particularly mental disengagement, behavioural disengagement, denial, self-blame and emotional strategies, with distress has been seen in relatives of people with schizophrenia (Friedman-Yakoobian et al., 2009). However, the same study did not find correlations between adaptive coping strategies and lower distress, which may have been due to the small

sample. In children of parents with mental illness, avoidant coping strategies were inversely related to both positive outcomes and to distress (Pakenham et al., 2007), and disengagement was linked to poorer adjustment and negative caregiving experiences (Fraser and Pakenham, 2009).

Chen and Greenberg (2004) have considered social support in terms of House's (1981) three broad categories and found that the presence of informational, instrumental and emotional support had a positive effect on caregiving gains (perceived positive changes due to caregiving). Social support might be a more important variable for caregiving outcomes than background characteristics, relationship with the ill person and living arrangements (Chen and Greenberg, 2004). Fraser and Pakenham (2009) showed that social connectedness in children of parents with mental illness was related to better adjustment and less adverse caregiving experiences.

However, the evidence for social support as a mediator in previous studies is less clear. For example, a study on carers of people with eating disorders failed to find a relationship between social support and carer burden or distress, although it set out to explore social support as a mediator between carer needs and outcomes (Coomber and King, 2012). Similarly, an earlier study on caregivers of persons with severe mental illness failed to find a relationship between social support and subjective burden(Webb et al., 1998). On the other hand, research on caregivers of people with Alzheimer's disease showed social support to be a moderator of the effect of perceived stress on caregiver resilience (Wilks and Croom, 2008).

Kinds of support

As with this research, the lack of information available to young carers of people with mental illnesses and the need for the same has been identified previously (e.g. Mordoch, 2010, Garley et al., 1997, Reupert and Maybery, 2007), with the lack of communication from health professionals seen as a separate theme (e.g. Lukens et al., 2002). However, few studies have been as specific as this thesis in the identification of the kinds of information required by young carers.

Young carers have also identified loneliness (Trondsen, 2012) and the need for a friend (Garley et al., 1997), but face challenges in confiding in other people about their experiences (Trondsen, 2012). Supportive adults and somebody to talk to were included

in ways of coping and ways of improving outcomes described by children of parents with a mental illness in Australia (Fudge and Mason, 2004). Mental health professionals described the impact on coping resources in adult carers of people requiring mental health services, through isolation, narrowing of social networks and full time commitments (Gray et al., 2010).

Aldridge (2006) has argued that, while parent-child relationships are interdependent, parents with mental illness retain their parenting status, indicating that the relationship with the ill person can continue to be supportive. The need for support from healthcare services and professionals was also identified in the Australian study by Fudge and Mason (2004). A small qualitative study with young carers of mothers with mental health problems identified the need for building close and trusting relationships (Grant et al., 2008). The study also teased out the elements of having one-on-one support and group support that are important for young carers: dependability, consistency and continuity were seen as being important for the former, while the latter included the opportunity to form new friendships, a sense of shared experience and respite. While similar support needs to those indicated by this thesis have been previously identified, stress process and social support theories have not been utilised in defining the types of support needed.

Outcomes

One of the key questions in the development of an intervention is identifying which outcomes it will target (MRC, 2008). Work with young adult carers has indicated that caregiving can be stressful and in extreme cases can lead to physical and psychological ill-health (Becker and Becker, 2008, citing Dearden & Becker, 2000). Carer distress was considered by this research as a potentially relevant target for intervention, one that could be used as a proxy for carer burden, which has been commonly used in studies of caregivers. The move from carer burden to distress as the negative outcome of caregiving experience has been argued earlier (Szmukler, 1996). Distress has been conceptualised as sadness, resentment, guilt, embarrassment and worry (Pakenham et al., 2006).

While the relevance of distress as an outcome was explored in the data, the aim was also to understand the meaning of distress in the narratives of the young carers. From the

qualitative study it could be seen that, while caregiving experiences could be distressing for young carers, distress was not always clearly described by participants. They talked instead about their experience as stressful and depressing, indicating that these might also be appropriate outcomes. This was supported by the nominal group which identified coping, feeling less stressed and feeling 'happier' as the desired outcomes of the intervention. Such psychological outcomes have been commonly used in formal randomised controlled trials (RCT) for this population, as seen in the systematic review, and there are valid and reliable instruments available to measure them.

In terms of outcome measures, there are two that are focused on this population: the Positive and Negative Outcomes of Caring (PANOC - YC20) was developed specifically for young carers (Joseph et al., 2009). The authors proposed the tool as a measure of the subjective cognitive and emotional impact of caregiving and suggested that it could be used to highlight concerns. Subjective feelings of stress, sadness, isolation and ability to cope are included as single item questions. Another measure that was developed specifically for young carers is the Young Caregiver of Parents Inventory (YCOPI) by Pakenham and colleagues in Australia (Pakenham et al., 2006) which, as the name suggests, focused on young people caring for parents rather than any other relative. The instrument aimed to measure the impact of caregiving and comprised two parts: one measuring caregiving responsibilities, perceived maturity, worry about parents, activity restrictions and isolation, and the other part measuring caregiving compulsion, discomfort and confidence.

Similar to this research, adult carers of people with SMI have previously described positive outcomes, including becoming sensitive to people with disabilities, clarifying their priorities in life, gaining inner strength, and becoming more patient and understanding (Chen and Greenberg, 2004). Becker and Becker (2008) also reviewed similar positive outcomes in their work on young adult carers: confidence and inner strength, closer relationship with parents, maturity, responsibility and other life skills, a caring attitude and understanding about illness and disability.

Recategorising themes

While most of the themes fit the stress process model by recategorising them according to the components of the model, some descriptive themes were not included. For

example, the main contribution of the support worker interviews to the research question was the barriers and facilitators identified. Thus, the entire interview transcript was coded and categorised into themes, but descriptive themes that emerged in the basic thematic analysis, such as 'support provided by young carer support workers and young carer projects', 'difference between caring for somebody with a mental illness and a physical illness', and 'defining young carers', were excluded from the model (see Appendix 4.3).

Adaptations from the adult carer model and implications

It is important to consider the differences found in this study, between the adapted young carer stress process model and the stress process model for adult caregivers. One of the main differences is that the secondary role strains and the secondary intra-psychic strains have been merged into one group of secondary stressors: this is primarily because there were fewer secondary stressors identified from the data. As with Pearlin's model, primary stressors are directly related to the mental illness itself. Since this is a model for severe mental illness, the stressors are different, although both models identify difficult behaviour as one of the primary stressors. The secondary stressors are derived from the mental illness or related to the caregiving situation. The connections between components of the model have also been simplified in the current adapted model.

In terms of the kinds of stressors that are likely to be specific to a young carer population: the young carer is less likely to have choice in taking on caregiving, particularly if family support is less, since leaving the situation is less of an option for children in a family. Taking on adult responsibilities as part of the caregiving role is also unique to young carers. Young carers feel they are less likely to be recognised for their expertise, since the focus tends to be on the adult carers in the family. Their dependence on adults for financial support is again specific to this population. While the support provided by young carer projects, through emotional and instrumental support, as a mediating factor for this population is similar to other carer services, the reduction in coping resources both within and outside the family may differ, since a young person may be more restricted in their access to social support. They may also have less access to informational support than adult carers, both through lack of recognition of their needs, as well as their dependence on adults for information.

Finally, outcomes such as being bullied and educational impact are likely to be specific to the young carer population, whereas isolation as an outcome in adult caregivers is debated (Robison et al., 2009).

While some of the differences between the experiences and needs of a young carer and an adult carer are already known, the adapted stress process model adds a framework for the process which might lead to negative outcomes in a young carer. Recognition of their role and ensuring that young carers have access to a range of support is key. Interventions for young carers which improve their coping strategies or provide missing elements of social support are also likely to be helpful.

Furthermore, stress appraisal has not been included as a separate factor in the adapted model for young carers, but Pakenham et al (2007) considered it as a variable in their study and did not find a relationship to distress or to positive outcomes. Szmukler and colleagues (1996) included their Experience of Caregiving inventory as part of caregiver appraisal in their model, but the components of the inventory are individual factors, which in this study have been incorporated as stressors or outcomes. Support for a stress-coping model for adults caregivers of people with psychosis has been reported previously, with a focus on the impact of caregiver appraisal and coping strategies on distress (Joyce et al., 2003). Ineffective coping strategies such as 'felt helplessness', 'inferred denial' and 'self-blame' were more strongly linked with caregiver psychological morbidity, as compared to appraisal which only showed an indirect relationship with outcomes, through other factors.

The stress process model in young carers: implications for support

Although previous research has identified young carers' support needs this study provides a theoretical framework for understanding the impact of young carers' experiences and providing interventions to improve their experiences. By comparing those who attended young carer groups with those who did not, it indicates how they can be better supported. Referral to a young carer project alone does not meet all individual needs. In spite of a considerable research literature on the experiences of adult carers and the relevance of the stress process model, it is still not clear what

components distinguish effective interventions for this population (Lobban et al., 2013). This research study contributes to current understanding of this question.

It is important to note that young carer projects and young carers families are likely to be able to provide only emotional and instrumental support. Even those who had access to young carer projects identified unmet needs and negative outcomes. Informational support of the kind indicated by young carers needs to be provided, and this is where services often fail young carers. The problem has been highlighted before in the young carer literature, but this model indicates that support will continue to be inadequate in removing negative outcomes if young carers do not have access to the different kinds of social support they need. Mental health services simply referring young carers to young carer projects is not sufficient on its own.

Further exploration of the relationship between receiving support and change in outcomes is also required. Participants in this study believed that their experiences had improved when they received support, but the relationship between the three kinds of support required and the impact on outcomes over time needs further investigation.

In addition, children who live with their family members with SMI and who may not have caregiving responsibilities, as well as those who continue to provide care although they no longer reside with their ill family members, need to be considered in terms of the potential impact and support needs.

The role of other models

The more cognitive models of caregiving focus on caregiver appraisal (Kuipers et al., 2010), and its impact on relationships and outcomes. Caregiver appraisal is understood within the context of the stress-appraisal-coping framework as the caregiver's estimation of the caregiving situation, seen as a potential stressor, in terms of its difficulty or demands on the caregiver, and the caregiver's estimation of their coping resources. This approach also includes the potential for positive appraisal or the perception of positive consequences (Kate et al., 2013). A young carer's initial appraisal of the illness and its impact on other outcomes are difficult concepts to explore in retrospective interviews, but there are indications of this in some of the themes. For example, the process of learning by which young carers can adapt to caregiving could be indicative of the role of reappraisal in the caregiving situation. This theme, and a

move to more cognitive models, can be explored further in future studies of this population.

Secondly, the stress process model as adapted to young carers supports a whole family approach. The family model (Falkov, 2013) is recommended as good practice for parents with mental health problems, in identifying the needs of the family as a whole and planning care packages. Similar to the model adapted in this study, there are risk factors and protective factors to take into consideration, but the interaction between parental mental health, parent-child relationship and child outcomes can be multi-directional. While supporting such a model, this study explores the experience of siblings of people with SMI, and identifies potential pathways for interventions for this population.

Interventions for this population

The systematic review in this thesis (chapter 3) identified that there is little evidence of effect for interventions for children and young carers looking after someone with an SMI. It indicated the dearth of theoretically-derived needs-based interventions, particularly for children caring for people with psychotic disorders. Taking this into consideration with work by Lobban (Lobban et al., 2013) and Bee (Bee et al., 2014), puts the qualitative study findings into context. The systematic review by Lobban and colleagues highlighted the difficulties with differentiating between effective and non-effective interventions for adult caregivers. However the most recent NICE guidelines for Psychosis and Schizophrenia 2014, found that information and support for adult carers was helpful, and these are now recommended interventions (Kuipers et al., 2014). Further, the systematic review by Bee and colleagues (2014) concluded with the need for carefully and rigorously developed child- and family-based interventions. The applicability of the stress process model and the need for different kinds of social support as shown in this thesis are important for developing interventions for this young carer population.

Social support has been shown to be an important predictor of outcomes in young carers (Pakenham et al., 2007), but this thesis has shown that young carers who had received some support still had negative outcomes. Social support theory suggests that ensuring all the different kinds of support (instrumental, emotional, informational) makes a

difference to outcomes in young carers, and preliminary indicators to this effect have been seen in this thesis. One could argue from the systematic review, which showed limited evidence of effect for a combination of interventions, that considering intervention components in terms of the kinds of social support provided and within the stress process model, might be more effective. While the findings of the qualitative study do not indicate a specific intervention, they highlight important elements for the development of an intervention. The qualitative study has shown that young carers feel the need for all three types of social support (informational, emotional and instrumental), and that positive coping strategies are also helpful in reducing negative outcomes.

While assessment of need is a familiar term in services for carers, it is not implemented uniformly (Dearden and Becker, 2004) and there are gaps in its provision. After an assessment of need based on the impact of the mental illness, a triage[11] approach could be used with different levels of intervention based on the level of need. A triage approach would not be new; it has been proposed before as part of an intervention for family members of someone with schizophrenia (Gamble, 2007). It has also previously been argued that the diversity in caregiver experience requires interventions that are tailored to the needs of the individual caregiver (Zarit and Femia, 2008), since caregivers vary on contextual factors, on their exposure and response to stressors, as well as on their coping resources and outcomes.

These interventions, as suggested by participants, need not be provided only by young carer projects. Indeed, it is likely to be more helpful for other services to provide some of these. For example, it has been suggested that mental health services need to provide tailored case-specific information about the illness and the patient's care (see results in Chapter 4), potentially by providing a service contact for the family. Informational support could also be provided by other means such as websites (e.g. www.mentalhealthcare.org.uk). Participants suggested ways by which schools could support young carers, which might help those who cannot access support from a young carer project. Where it might be inappropriate or a service might not be able to provide something directly (e.g. intense intervention, meeting other young people in a similar

[11] Initially used in medicine, the term triage is used to denote the treatment of patients based on the degree of urgency of the wound or illness. In the context of this research, it denotes providing a degree of support for a young carer based on the level of need.

situation), they can ensure a young carer is signposted to a service that does provide this. What is significant about involving other services in the provision of interventions is that it could reduce the burden on young carer projects, reduce the gaps in services for young carers and ensure that young carers do not miss out on support. Using the stress process model strengthens the argument for other agencies to be able to provide support through increasing positive coping strategies and supportive systems.

Crucially, pathways to care depend on services identifying children living with somebody with a severe mental illness. The guide produced by the Social Care Institute for Excellence for staff in mental health and children's services provides detailed recommendations for good practice for the screening, assessment, planning and provision of care, and reappraisal of care plans of families with a parent with a mental health problem (SCIE, 2009).

The importance of early intervention has been highlighted previously and this would depend on prompt identification by services. Aldridge (2008) acknowledges that early intervention is difficult because of the desire for concealment within the family and that it will only be possible when children are able to talk openly about their experiences without fear of stigma or other consequences. Provision of support through schools could again be a means for preventive and early intervention for young carers, but this would depend on the societal issue of combating stigma.

An important question is whether an effective intervention would need to be a family intervention or would need to include a component for parents. This has been suggested previously (e.g. Reupert and Maybery, 2009). Many of the interventions in the systematic review were family interventions. There has been a growing call for services to consider the needs of families (Evans and Fowler, 2008, SCIE, 2009), although the guide by SCIE (2009) calls for family support alongside individual support for parent and child. Young carers highlighted better support for the family and the person cared for as the change that would have the greatest impact on their lives (HM Government, 2008).

Ideally, services to support young carers, would be the result of strategic planning, cross-service communication, service coordination and awareness of young carers needs. Collaboration between services is particularly important to ensure that young

carers are identified. The idea of an appointed liaison worker to work between mental health services and young carer projects is one way to ensure that young carers' needs are being met. Aldridge and Becker (2003) have highlighted the importance of a whole family approach and inter-agency collaboration and information-sharing.

Limitations of the study

It can be argued that the inclusion of young adults aged 16-25 for the study sample does not take into consideration the differences between young adult carers (18-24 years), those aged 16-17 years, and young carers (below 16 years). Since the issues specific to young adult carers have been identified in earlier research (see Becker and Becker, 2008), this study focused on the issues previously faced by young carers, but notes the issues related to transitions to adulthood. Most importantly, this study enabled a retrospective account that allowed participants to reflect upon their earlier experiences, the support received and the perceived impact on their lives. While children do provide competent accounts and valuable perspectives in research in this population (e.g. Aldridge and Becker, 2003), retrospective accounts can also be helpful in enabling greater self-understanding as participants look back at their experiences over time (e.g. King et al., 2006).

Secondly, the size of the study sample (1 focus group from a young adult carers service, 14 in-depth interviews of which 13 participants were distinct from the focus group, 1 nominal group with selected interview participants, and interviews with 7 young carer support workers) was small. However, as Table 4.1 in the results section indicates, the participants came from a range of backgrounds, geographically spread across England, and included minority ethnic groups. The people for whom they provided care were both parents and siblings, with a range of severe mental illnesses. Small samples are intrinsic to qualitative research (Miles and Huberman, 1994), facilitating the study of personal accounts in depth.

Furthermore, the size of the sample might have limited theoretical saturation. Further exploration of the stress process model, for example by applying the model to new cases, would have added new insights. It also meant that differences between cases could not be explored in detail.

The sub-sample of young adults who did not receive support from a young carer project also has limitations: most were recruited through the University, which has implications for representativeness. However, this is one of the few studies to include a sub-sample that was not already receiving support.

The limitations in the systematic review - exclusion of interventions through parents that might affect child outcomes, the inability to completely duplicate the SCIE search, and the low Kappa value of agreement between researchers - have been discussed in that chapter. While a meta-analysis is to be preferred for its evaluation of the cumulative effectiveness of interventions, a narrative synthesis allows the findings of the review to be explored in detail and summarised.

The issue of power relationships between researcher and participant is one that has to be considered, since the researcher had experience of caregiving and utilised this for the research. While stakeholder involvement is an advantage in its ability to give the subject under research a voice, and command over the research, the absence of a formal stakeholder advisory group raises issues around the researcher's power in directing the research. However, this was ameliorated by consultation with two other researchers with experience of caregiving, as well as involving senior academics with experience in research with carers in the validation of themes (see page 61). Furthermore, while the researcher sets the agenda, the participant also has some control in the power differentials through the informed consent process and through the knowledge produced (Ben-Ari and Enosh, 2012). The same authors hold that the power relations are dynamic and shift throughout the research process. Thus mutual contribution and a common interest in the subject under study may offset the impact of power differentials. Strong interest in the subject was shown by participants who volunteered in response to the advertisement (see Appendix 2.4). The researcher's declared experience was seen as a way of empowering participants during the research. Additionally, methods such as feeding back the results to a smaller group of participants (the nominal group) and to support workers sought to verify and expand the researcher's understanding of the topic.

Finally, while it would have been helpful to be able to study this further (see change in protocol in Chapter 2), either by piloting an intervention or by quantitatively comparing outcomes in those with and without support, the time restrictions on the thesis mean that this will have to be implemented in further research.

Strengths of the study

This thesis is one of the few pieces of research on this population that has recruited both young people who were supported by young carer projects as well as those who did not receive support. Although the sample was small, this enabled a qualitative exploration of the impact of young carers' services. It indicates that those receiving support from young carers services have further support needs, and the stress process model can be adapted to understand these needs.

- Recruitment of both siblings and children of people with SMI has enabled further understanding of the different experiences of these two groups of caregivers, since previous studies have focused either on siblings or on children of people with SMI. For example, the results indicate that there are qualitative differences in the level of support available to children and siblings of people with SMI.

- In drawing together research on young carers, children and siblings of people with severe mental illnesses, it examines the difference between those living with and caring for somebody with a mental illness.

- This study was designed and carried out by a researcher with experience of living with and caring for SMI. Stakeholder research supports the constructivist paradigm by incorporating multiple perspectives and adds a layer of authenticity when developing evidence-based policy (Rose et al., 2006).

- The combination of the "bottom up" approach of the qualitative study with the "top down" systematic review of current interventions has produced a broader theoretical understanding of young carers' needs and preferences for support, to complement the findings on effectiveness of interventions provided thus far.

- The results indicate that the stress process model could prove useful by indicating the kinds of support required by young carers. Furthermore, it provides a theoretical understanding for the negative outcomes sometimes also seen in those who do receive support, by providing a framework for the different types of support (informational, instrumental, emotional) that are important for this population.

CHAPTER 6: CONCLUSION

This chapter draws together the previous chapters and summarises the thesis. It looks at what the findings mean in terms of the MRC guidelines for complex interventions and considers the implications for practice and policy.

Returning to the MRC guidelines

As described in the methodology in Chapter 2, the thesis was based on the MRC guidelines for complex interventions, trying to identify mechanisms for interventions for young carers of people with SMI. The learning in line with the intervention development stages outlined earlier is discussed below.

Identifying the evidence base

The systematic review of interventions in this thesis and previous reviews have shown little evidence of effect of interventions for this population of young carers of people with SMI. The systematic review provided limited support for the stress process model in indicating that a combination of cognitive-behavioural and family psycho-educational interventions could be helpful in improving anxiety and coping outcomes. However, there is, in addition, a need for interventions that are based on a theoretical understanding of the mechanisms by which they might work, since existing interventions are focused on the risk to children from parental mental illness. There is also a lack of scientific evidence for interventions that support children with caregiving responsibilities, focus on child outcomes, and on young carers of people with psychotic disorders.

The argument for interventions notwithstanding, evidence from relatives of people with psychosis has indicated little difference between effective and non-effective interventions in terms of their intervention components (Lobban et al, 2013). Even categorising intervention components according to psycho-education, skills training and mutual support (which is similar to the categories of social support) failed to find a difference. However, research on carers of people with eating disorders has shown that a theoretical understanding of the stress process model can be helpful for designing and developing interventions to support them. For example, deconstructing the kinds of

support perceived as helpful by caregivers and its actual impact on distress can be helpful in advising the kinds of caregiver skills on which an intervention should focus (Raenker et al, 2013).

Developing theory

The stress process model was applied to the thematic analysis of the qualitative data to explore its suitability as a theoretical framework for the experience of young carers looking after somebody with an SMI. The findings indicated that the model was helpful in delineating the factors that might contribute to a stressful experience, and the factors that might be supportive and reduce negative outcomes.

The kinds of information and support required for young carers of people with SMI has been known to some extent and has been discussed in the previous chapter. This study has utility, because it provides a model within which young carers' experience can be understood and intervention provided. More importantly, by comparing those who have received support and those who have not, it indicates where the gaps are and how they can be better supported. What this shows is that a stop-gap approach will not work if the gaps (i.e. support needs) are not identified individually. As previously known, referral to a young carer project alone is not the answer.

Having a carer perspective while leading the research has been important: the researcher supports the notion that young carers should not merely be viewed as a population at risk. It does not counter a disability rights perspective on young carers, by supporting the rights of this population as children and as carers. While it does acknowledge the risk of negative outcomes, the use of a stress process model lies in identifying those factors that contribute to the experience and particularly the kinds of support that are needed to improve outcomes.

More recently, cognitive models have been used to explain caregiving in psychosis (Kuipers et al., 2010), and a move to these more advanced models would be the next logical step in understanding the relationships between caregiver and patient variables. These models focus on caregiver appraisal, which is more difficult to explore as retrospective data, but still demands exploration in this population of young carers in future research. Nevertheless, it makes an important case for exploring the relationship between caregiver response and patient outcomes. These models also highlight the

significance of the whole family approach in supporting families affected by SMI, since the dynamics of the relationships between family members plays an important role.

Modelling process and outcomes

This step will be dependent on further quantitative testing of the relationships between factors in the model. The qualitative study has indicated that different kinds of social support (instrumental, emotional, informational) are required to improve outcomes, and the impact of providing these kinds of support, the change in outcomes, and the factors that need to be controlled can be assessed quantitatively. However, looking at the adapted model indicates mechanisms by which an intervention might be effective. The primary and secondary stressors are likely to be similar across young carers, whereas the contextual factors might vary and need to be taken into consideration. The main points for intervention are in enhancing the coping strategies utilised, and in increasing the coping resources and support available. On the other hand, those who have received some support have still had negative outcomes, and this thesis makes the case for providing the different kinds of support needed based on social support theory, to address the gaps. The process of learning and adaptation that a young carer goes through over time also would need to be taken into consideration.

Implications for policy and practice

The same kinds of support have been shown earlier in the literature to be helpful for adult carers with SMI, and in other young carer literature, but little progress has been made in providing this care. The Children and Families Act 2014, which recently became law, requires a United Kingdom local authority to assess whether a young carer in their area has needs for support. The assessment must take into consideration the appropriateness of the caregiving and the young carer's own desires, including the wish to take part in education/work/recreation. This stresses the responsibility of local government services in supporting young carers (see also Care Act 2014).

The NHS is currently undergoing a time of strategic change with the Health and Social Care Act 2012. The shift to empowering healthcare professionals may increase the potential support for young carers. This is particularly crucial for ensuring that all

young people in families with a severe mental illness, not just caregivers, have a chance to be assessed for need and directed to adequate support. On the ground, however, this can be reduced to referrals from mental health services and other local services to young carer projects. On the other hand, recent cuts to funding are having an impact on young carers services, which are foreseen to have an impact on direct contact with young carers because of the reduction in the number of staff hours (Action for Children, 2013). In their report, Action for Children also makes the call for longer term planning that focuses on early intervention for families in need.

The recently passed law also takes some young adult carer needs into consideration by looking at their desire to participate in education, training or work. However, it does not distinguish them as a group with distinct needs, as recommended Becker and Becker (2008). Furthermore, in Becker and Becker's report (2008), they made recommendations for the provision of young adult carer services, including early intervention and a whole family approach. Since then, little has changed, with a recent report (Sempik and Becker, 2014) highlighting the fact that young adult carers who go on to further or higher education still struggle to balance their caregiving with their education. It also highlighted the importance of support through young carers services for positive outcomes.

There is support available for young carers, indeed, some young carer projects are already providing the important elements (information, somebody to talk to, meeting other young carers) and more (parenting support interventions, advocacy). However, support for young carers is thinly spread and patchy. There needs to be a strategic approach to ensure uniform support. This research has shown that support for young carers can come from different sources and that healthcare professionals and health services have an important role to play. Support will be enhanced if different service providers work in partnership to identify this population and meet their needs.

The drive towards localised services and empowering people and communities to take responsibility for their own well-being (HM Government, 2011) is likely to increase carer involvement in service development. The Government's focus on achieving outcomes and the consequent effort towards integrated services fits in with the suggested intervention and may further a multi-agency approach. While a strategic approach that includes whole families has been argued for some time now, barriers to

partnership working between services still remain, in spite of attempts by both research and policy to overcome this. SCIE produced guidelines for family-focused services including cross-agency working (SCIE, 2009) and, in practice, sites found ways to implement strategic working (SCIE, 2012). However, they still faced barriers, in particular relating to measurement of service user outcomes and support at a senior level.

Most importantly, the focus is now on a whole family approach. With the Government committed to enabling carers and young carers to fulfill their education and employment potential (HM Government, 2014), and best practice focused on identifying the needs of children in families with mental health problems in providing services (Falkov, 2013), there is a strong argument for interventions which follow clearly indicated theoretical lines.

While the responses from the support workers interviews added relatively little that was not already identified, they did extend the model by indicating the current barriers to providing support. Despite evidence of need, there continue to be difficulties faced in providing adequate support for young carers, and the support provided is not always consistent or sufficient. While not entirely novel, the model for young carers developed here provides the first step in the process of developing an intervention for this population. Contemporary mental health research has been focusing on identifying and testing effective interventions, alongside a move to find solutions that lie outside overburdened health services (e.g. Patel et al., 2007, Collins et al., 2013). An intervention based on this theoretical development which addresses coping and the different kinds of support required, would be the next step in the process of ensuring that young carers have the support they need, alongside a move towards collaborative service provision and a whole family approach.

Another key point for policy and practice is the use of the term young carer. Given that few participants saw themselves as young carers, and that impact can be felt without living with the person with SMI or having specific caregiving responsibilities, services for young carers will have to word their promotions carefully in order to ensure that the targeted population does not see the service as being irrelevant to them. A whole family approach will aid the support of all young people affected by SMI in the family.

In summary

The systematic development of an intervention for young carers of people with SMI is an essential gap in their support that needs to be filled. This thesis used the stress process model to identify the kinds of informational, emotional and instrumental support needed by young carers, and the other factors involved in predicting outcomes, to indicate the mechanisms for intervention. However, the elements of support identified by young people themselves will be important for developing interventions that are effective and trials of effectiveness will have to take into consideration the other influential factors outlined in the adapted model. Furthermore, tests of effectiveness will have to look beyond the standard RCT design to take into consideration the multiple factors involved such as collaborative care approaches and working with whole families (Lobban, 2013).

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APPENDICES

Appendix 2.1: Information sheet given to participants

PARTICIPANT INFORMATION SHEET 17122009 - v2.1

UNDERSTANDING THE EXPERIENCE OF YOUNG CARERS WITH AN AIM TO REDUCE CARER DISTRESS
National Institute of Health Research (NIHR) Biomedical Research Centre for Mental Health (BRC) Young Carers' Project

Thank you for your interest in our study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. One of our team will go through the information sheet with you and answer any questions you have. We would suggest this should take about 15 minutes. You can also talk to others about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).
Please do ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

Part 1

Purpose of the research
We are conducting this study to understand the experience of young carers, in particular to find out what is distressing for them, and to get their advice on developing something that will help them. We hope that the results of the study will be useful in developing services for young carers.

Why are we inviting you to take part?
As a young carer for someone with a severe mental illness, we would like to draw on your expertise to better understand the experiences of young carers.

Do you have to take part?
It is up to you to decide to join the study. We will describe the study and go through this information sheet, which we will then give to you. If you agree to take part, we will then ask you to sign a consent form to show you have agreed to take part. You will be given a copy of the signed consent form to keep. You are free to withdraw at any time, without giving a reason. This will not affect your rights and the care given to the person with the illness will not be affected by your withdrawal.

What is involved?
We will ask you to take part in a focus group - a group interview/discussion with other young carers. If you are not comfortable with doing this, we could do an individual interview with you. The focus group will be approximately two hours long since it involves a group of people. The individual interview will not last more than an hour.

If you consent, we will also invite you to return to our study for a second focus group (2 hours) and ask you to fill out some questionnaires (30 minutes).

We will also be inviting participants to take part in a nominal group. The nominal group will be given the analysed results to read and will discuss them in order to arrive at a consensus. The nominal group discussion will take approximately two hours.

The discussion in all the focus groups and interviews will be digitally audio-recorded with your consent so that we do not miss anything important, and then the recording will be transcribed into text for analysis.

Expenses and payments
We appreciate the time and effort you have spent and, at the end of the focus group/ interview, you will receive a £10 gift voucher to recompense you for your time and your travel expenses will be reimbursed. Participants who take part in the nominal group or further focus groups will be similarly reimbursed.

Confidentiality
All personal data will be kept absolutely confidential and limited to the research team (Ms Joanna Murray, Prof Elizabeth Kuipers, Miss Anisha Siromoney, transcribers). As the data is transcribed, we will remove any details that might identify you, so that the transcribed data is anonymous. This anonymised transcribed data may be used in our publications or for teaching purposes in addition to further analysis.

Data protection
The data will be stored in accordance with the Data Protection Act (1998). The digital recording will be stored in a password-protected account on the Institute network and physical data (consent forms and questionnaires) will be stored in locked cabinets. Soft copies of questionnaires will only have participant numbers rather than names.

With your consent, we will keep your personal information in order to contact you about further participation in this study and the subsequent pilot study.

Possible disadvantages and risks
You might find talking about your experience as a young carer distressing. We will do everything we can to be as empathic as possible. The Chief Investigator (Anisha Siromoney) has been a young carer herself and can understand what it is like, though no two experiences are ever the same. If you still feel upset at the end of the interview/ focus group, please do let us know. If this happens, a senior clinical psychologist, Prof Elizabeth Kuipers, will be consulted.

If you have any complaints (or suggestions), please let us know immediately and we will do everything we can to assist you. If you do not feel that your complaint has received an adequate response, you can go through the Institute of Psychiatry Complaints Procedure via the Dean's Office, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.

Benefits of taking part
The project will not have a direct benefit for you, although you will get to meet and socialise with other young carers, but we hope that the results will shed some light on the experience of young carers and be beneficial to them in the future.

Part 2
Withdrawal
You do not have to take part in the study and you are free to withdraw at any time, without giving a reason, and your data will be removed from the study. Withdrawal from the study will not affect you or your family in any way.

What happens if things go wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the Institute of Psychiatry Complaints Procedure via the Dean's Office, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.

Harm
In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the Institute of Psychiatry, King's College London, but you may have to pay your legal costs.

What will happen to the results of the research study?
The results of this study will inform the next stage which will be a pilot intervention intended to help young carers and reduce distress. This study will be written up as part of the Chief Investigator's doctoral thesis. The results will also be published in scientific journals, conferences, etc. If you so wish, we can send you a copy of the results and publications once the research has been completed.

Who is organising and funding the research?
The study is being conducted as part of the work done by the NIHR BRC's Stakeholder Participation Theme at the Institute of Psychiatry, King's College London. The study has received approval from the Ealing & West London NHS Research Ethic Committee (REC Ref 09/H0710/65)

Contact details of the researchers
If you have any other questions, please do not hesitate to contact
Mrs Anisha Lazarus (Chief Investigator)
Health Service and Population Research Dept
P026 Institute of Psychiatry
De Crespigny Park
London SE5 8AF
Tel: 020 7848 0125
Fax: 020 7848 5056
Email: anisha.lazarus@kcl.ac.uk
Thank you for considering participating in this study.

Appendix 2.2 Participant consent form

PARTICIPANT CONSENT FORM 17122009 V2.1
PARTICIPANT'S COPY

UNDERSTANDING THE EXPERIENCE OF YOUNG CARERS WITH AN AIM TO REDUCE CARER DISTRESS
National Institute of Health Research (NIHR) Biomedical Research Centre for Mental Health (BRC) Young Carers' Project

Please fill this form only after reading the Participant Information Sheet (17122009 v2.1), and only if you have no further questions or need for clarification and you are willing to take part in the study. Please fill in your name and put your initials in the box for each statement with which you agree. Please sign and print your name and date your signature at the end of the form. Thank you!

I ……. have read the Participant Information Sheet (17122009 v2.1) for the National Institute of Health Research Biomedical Research Centre Young Carer Project.

□ I consent to taking part in this project.

□ I understand that I do not have to take part in this study and that I am free to withdraw at any time. If I withdraw, my data will not be used in the study.

□ I consent to the interviews/discussions being digitally recorded in order for them to be transcribed accurately

□ I consent to my anonymised data being used for teaching purposes and publications and further analysis.

□ I consent to my personal information being stored securely by the research team in order to contact me for further participation in this project and the subsequent pilot study.

□ I understand that anything discussed remains within the group and agree to respect the privacy of other participants by keeping the discussion confidential.

Signature of participant:

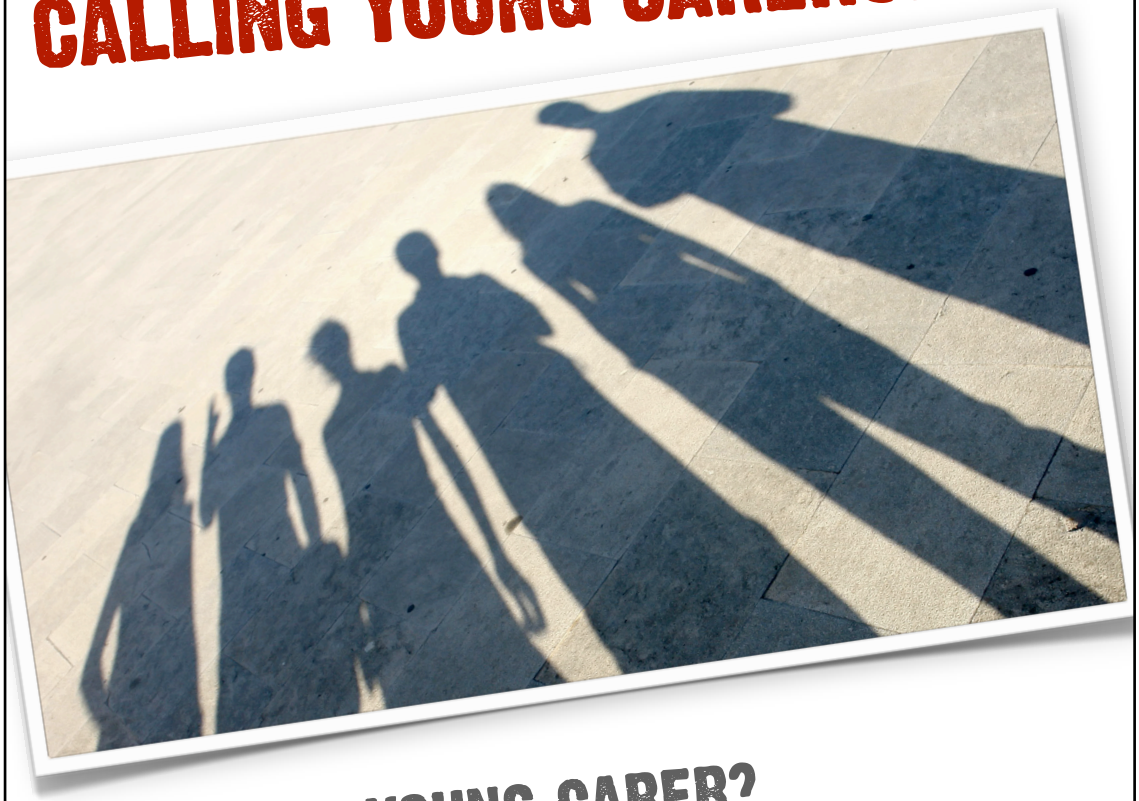
Print name:

Date:

Signature of researcher:

Appendix 2.3: Recruitment poster

CALLING YOUNG CARERS!



ARE YOU A YOUNG CARER?
DO YOU LOOK AFTER SOMEONE WITH A SERIOUS MENTAL HEALTH PROBLEM?
16-25 YRS OLD?
THEN WE'D LIKE TO MEET YOU!

THE YOUNG CARERS PROJECT

WE WANT TO UNDERSTAND THE EXPERIENCE OF BEING A YOUNG CARER - THAT'S WHY WE'RE INVITING YOU, AS THE EXPERTS, TO TAKE PART IN OUR STUDY AND HELP US TO BETTER UNDERSTAND THE NEEDS OF YOUNG CARERS AND TO GIVE US SOME ADVICE ON WHAT MIGHT HELP YOU.

PS: I WAS A YOUNG CARER TOO SO I'D LIKE TO KNOW MORE ABOUT OTHER YOUNG CARERS' EXPERIENCES

INTERESTED?
CALL 020 7848 0125
OR EMAIL
anisha.siromoney@kcl.ac.uk

26.10.2009 v1.1

Appendix 2.4: Recruitment poster after amendment on advice of participants

DOES SOMEONE IN YOUR FAMILY (FOR E.G. PARENT/SIBLING) HAVE A SEVERE MENTAL HEALTH PROBLEM?

HAVE YOU HELPED LOOK AFTER THEM?

ARE YOU 16-25 YRS OLD?

WE WANT TO UNDERSTAND THE EXPERIENCE OF YOUNG PEOPLE WHO LIVE WITH SOMEONE WITH A MENTAL ILLNESS AND LOOK AFTER THEM IN SOME WAY OR HAVE DONE SO IN THE PAST. THAT'S WHY WE'RE INVITING YOU, AS THE EXPERTS, TO TAKE PART IN OUR STUDY AND HELP US TO BETTER UNDERSTAND YOUR NEEDS AND TO GIVE US SOME ADVICE ON WHAT MIGHT HELP YOU.

INTERESTED?
CALL 020 7848 0125
OR EMAIL
anisha.siromoney@kcl.ac.uk

03.08.2010 v2.1

Appendix 2.5: Preliminary topic guide

NATIONAL INSTITUTE OF HEALTH RESEARCH (NIHR) BIOMEDICAL RESEARCH CENTRE FOR MENTAL HEALTH (BRC) YOUNG CARERS' PROJECT

Understanding the experience of young carers with an aim to reduce carer distress

PRELIMINARY TOPIC GUIDE

BROAD TOPICS (Garley *et al*, 1997)	EXAMPLES OF PROBE QUESTIONS
Carer personal - education work life at home leisure friends time/time spent	How do you spend your time? What are you doing nowadays? What has been the biggest change in your life since you learnt that your ------ was ill?★
Patient - personal/relationship illness	Can you tell me about the person you care for?
Illness - knowledge/awareness coping difficulties good points	What do you understand about this illness?★ How do you cope when your mother/father is ill? ★ What are the kinds of difficult situations you had to face and how did you cope with them? Who do you ask for help when you need it? ◊ What is your greatest concern related to the illness?★
Views on caring	Did you think of yourself as a young carer? ◊ Do you think of yourself as a young carer now? ◊ How do you think caring for (…..) affects you? ◊
Advice for other young carers	What do you think would be helpful for other children in your same situation?★
What I like and dislike about caring‡	
Intervention	What kinds of things would help you right now?◊
Existing interventions	What do you think of….? Was it helpful for you?
Relevant measures	

(◊ Barnardo's (2003) Meeting the needs of black and minority ethnic young carers: a literature review and research study for the Willow Young Carers Service. London: Barnardo's.

★ Garley, D., Gallop, R., Johnston N., Pipitone, J. (1997) Children of the mentally ill: a qualitative focus group approach. Journal of Psychiatric and Mental Health Nursing, 4: 97-103.

‡ Joseph, S., Becker, F., Becker, S. (2009) Manual for measures of caring activities and outcomes for children and young people. London: The Princess Royal Trust for Carers.)

Appendix 2.6: Evolution of topic guide through data collection

NATIONAL INSTITUTE OF HEALTH RESEARCH (NIHR) BIOMEDICAL RESEARCH CENTRE FOR MENTAL HEALTH (BRC) YOUNG CARERS' PROJECT

Understanding the experience of young carers with an aim to reduce carer distress

TOPIC GUIDE

BROAD TOPICS (Garley *et al*, 1997)	EXAMPLES OF PROBE QUESTIONS
(5)Carer personal - education work life at home leisure friends time/time spent	Can you tell me a little about yourself? Age? What are you doing nowadays? How do you spend your time? Do you live with the person you care for? How many hours pw do you think you spend caring?
(10)Patient - personal/relationship illness	Can you tell me about the person you care for? When did the illness begin? When did you start caring?
(15)Illness - knowledge/awareness coping difficulties good points	What do you understand about this illness?★ Do you know what's happening when ___ goes into hospital? How do you cope when your ----- is ill?★ What are the kinds of difficult situations you had to face and how did you cope with them? Who do you ask for help when you need it? ◊ Do you feel you have enough general information to support you? Where do you get the information from? What is your greatest concern related to the illness?★ What has been the biggest change in your life since you learnt that your ------ was ill?★ How did other people's opinions affect you as a child? What happened when you first voiced your concerns? Have you ever worried/felt guilty about that? Did it affect your schooling? What were the issues there? Have you had to miss school/Uni/work because of caring?

BROAD TOPICS (Garley *et al*, 1997)	EXAMPLES OF PROBE QUESTIONS
Distress	Do you think the term applies to any part of your experience? What did you find distressing? Was there anything which helped to reduce your distress? If so, what?
Views on caring	Did you think of yourself as a young carer? ◊ Do you think of yourself as a young carer now? ◊ How do you think caring for (…..) affects you? ◊ What do you rely on each other for? How does this affect your relationship?
Advice for other young carers	What do you think would be helpful for other children in your same situation?★
What I like and dislike about caring‡	
(35)Intervention	What kinds of things do you think would have helped?◊ What made you think, either then or later, "Oh if only I had had that!"?
Existing interventions	What do you think of….? Was it helpful for you?
Relevant measures	
Emerging themes	How long has ____ been diagnosed? When did you first start caring? How were you involved in the path to treatment?
(50)Anything else?	Is there anything else that you think we could have discussed? Anything that you feel is very important?

(◊ Barnardo's (2003) Meeting the needs of black and minority ethnic young carers: a literature review and research study for the Willow Young Carers Service. London: Barnardo's.

★Garley, D., Gallop, R., Johnston N., Pipitone, J. (1997) Children of the mentally ill: a qualitative focus group approach. Journal of Psychiatric and Mental Health Nursing, 4: 97-103.

‡ Joseph, S., Becker, F., Becker, S. (2009) Manual for measures of caring activities and outcomes for children and young people. London: The Princess Royal Trust for Carers.)

Appendix 2.7: Initial thematic analysis

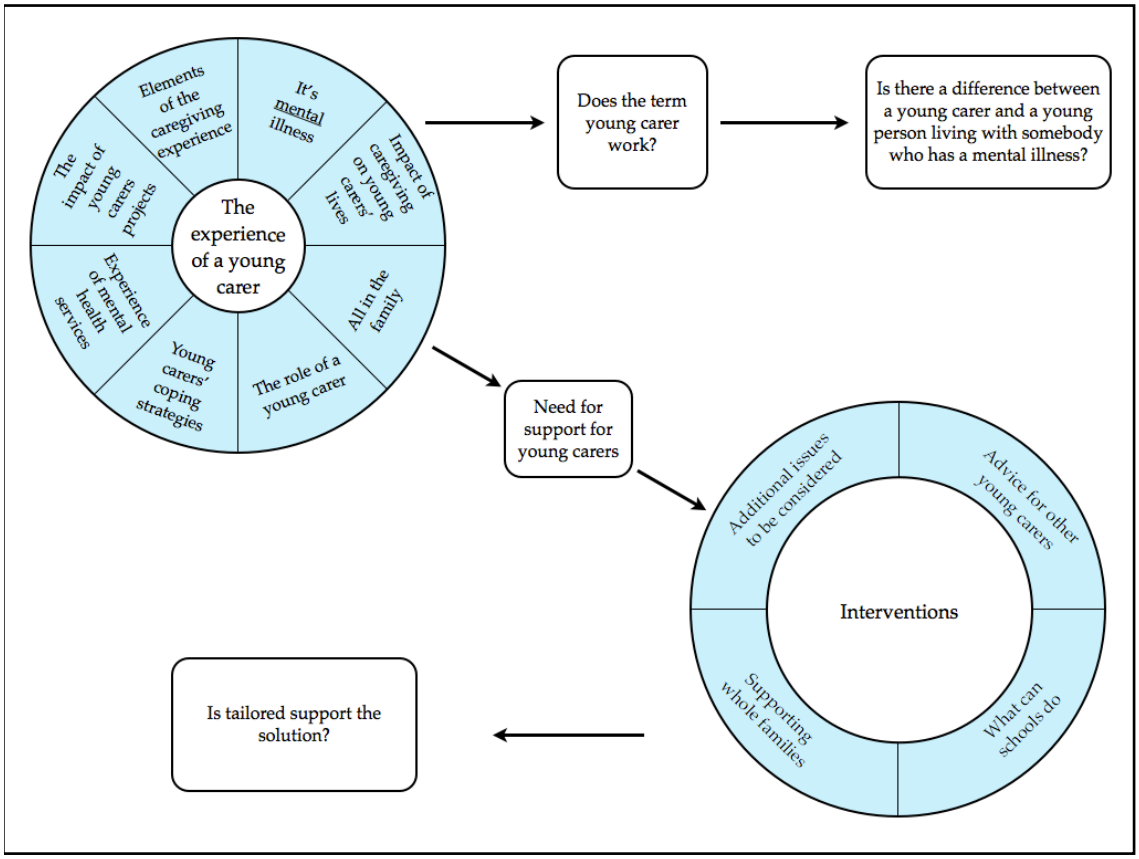
The experience of a young carer: Findings from the interviews

The experience of young carers looking after somebody with a severe mental illness can be described through the following common themes, identified in the interviews with participants.

Elements of the caregiving experience

The elements of the caregiving experience include young carers' descriptions of their experience, their concerns, the level of choice in taking on a caregiving role, what young carers found difficult about caring for somebody, understanding the experience of caregiving at a young age, and understanding the transitional stage of a young carer's experience.

4.1: A summary of the findings from the qualitative study



Young carers' descriptions of their experience

Participants' descriptions of the caring experience ranged from awkward and embarrassing (participant who lived with mother with obsessive-compulsive disorder) to chaos and destruction (participant caring for mother who is manic depressive) and even tragicomic (i.e. both funny and distressing). Irene described dealing with her mother's manic depression as exhausting and draining. Caring could be difficult, and some young carers felt they could not live a 'normal' life.

AL: How did you feel about things?
Enid: I think it's always difficult, and I think, maybe now, I find it upsetting and sad but not, I think this time when she was ill was the only time where I hadn't sort of been there while she was ill and I think if you were just with somebody, with your mum who is obviously very ill and it's really hard and it's hard work and you don't get to sleep and this sort of thing, then it's very emotional and very difficult.

Simon and Tarun described it as caring by trial and error. Others also described it as a process of learning, wherein through experience, as time went by, they learnt about the illness, how it expressed itself and what they needed to do.

AL: And how have you found out how to act?
Simon: Well you know it's been a process of learning, when these things happen what works best and what doesn't work if you see what I mean.
AL: So as in, each time something happens…
Simon: Yeah trial and error, if you see what I mean.

Their perspective of the caring experience could also vary as things changed; Naima described it as devastating then relieving then rewarding. Caring could involve a change in their roles, with even a certain amount of role reversal. They sometimes had no one to look after them, and they frequently had to be more grown-up than they would normally need to be.

"...and you expect your parents to deal with these things, you don't have an adult that you can turn to so what the hell do I do, so you just have to get on with it." Pauline

"So it was quite difficult to go from like him being this guy that I really looked up to to like being somebody that sort of I had to look after, and it annoyed me that I had to look after him because he was older than me and he's the one that's meant to look after me. And then I'd feel bad because it annoyed me and he's my brother so yeah." Beatrice

<u>Young carers' concerns</u>

The main concerns of participants (what worried them or made them anxious) related to the person with the illness rather than themselves. Mandy was concerned that ignorance about mental illness could mean that people's mental illnesses were left undiagnosed, or that family members might be unaware of the importance of care after hospitalization. Young carers were particularly concerned that the people they were caring for could inadvertently be a threat to themselves or to other people. Antonia was worried that her father might ruin his life. There were also concerns about recovery: participants were worried that their relatives might get ill again, or that they might never recover fully, or that they would not have a normal life. Rajini was worried that her mother might be hospitalized, and that she could lose her mother to the illness.

AL: What was your biggest concern with your brother's illness?
Simon: That he was gonna hurt somebody else or himself. Pretty much more that he was gonna hurt somebody else. That was the biggest concern.

"Looking back I think it was, it still is, that she's never actually going to be well and she's never going to be off the tablets. Is it something that she's going to be on for the rest of her life? Am I always going to have to cope with the fact that she's going to have good months and bad months and yeah, each year is going to be different, and the fact that she can't cope with my stresses or any stress at all. I think that's my biggest worry at the moment and it probably was back then as well, because you can't see the end of the tunnel." Clover

Pathway to caring

This theme explores the point at which young carers began to take on caregiving responsibilities - when they became young carers - and the factors that led to this. With some of the narratives the pathway to caring was not clear. With the others, the beginning of caregiving was understandably related to the onset of the mental illness and the departure of other family carers. Thus, Simon had always looked after his younger brothers and continued to look after them after his brother's mental health problems began, since his parents were working full time. Naima's family began caregiving when her sister became ill. While Irene's mother had been ill before, there was a period of stability during which Irene moved back with her mother, so she was the only family member around when her mother fell ill again.

With Mandy and Naima, their caregiving was initially tempered by their need to understand that it was a mental illness. As Beatrice grew older, she took on more responsibility for her older brother because her parents were working full time and her older siblings no longer lived at home. Young carers sometimes realised only later that they had begun providing care.

"I think it was when we got the puppy because that's when I really needed, yeah I think looking after a dog and like bringing up a child, that was when I really realised that I was actually looking after my mum as well, because it then became very difficult to do everything and that was when I noticed that my brother wasn't around." Clover

Choice in taking on a caregiving role

Some young carers felt that they had little choice in taking on a caring role – they "fell into" the role, usually because there was no one else.

"She had a financial stress I think that did it really, so that just somehow into this depression really quickly, came really quickly. And obviously by that time she wasn't with my dad, she's not been with him for years and years, and my brother'd moved and her family all live in **** so it was just me." Irene

"Maybe, I think it was just more difficult for her [older sister] because actually... so I was sort of 10 or 11 when my parents split up whereas she was 15, 16, and actually at that time my dad was around, other people should have been dealing with things and they weren't. And I think 'cause there was that confusion that actually nothing was being done but she shouldn't really the person that should be doing stuff, that was difficult, whereas by the time I got to that age it was just me, so I knew that it was me that was doing stuff and it wasn't, there wasn't anyone else around but that was OK, it wasn't like there were people there and they should be doing things." Enid

Of the nine participants who were caring for a parent (including one who cared for both a parent and a sibling), in eight cases they were each the only person available at that point to take on the caring role. Three had older siblings who had moved away and two of these older siblings had previously been the main carers. The majority of the parents with mental illnesses had separated from their partners. The exceptions were Arthur's parents, both of whom had health problems, and Clover's father who was looking after her mother but also had to work. However, as Clover indicated, she had little option in caring in spite of her father's role.

"…it was just something that was going through my life, that was happening. I think it was something that was, there was no option, I was just caring for my mum and so, I don't know really." Clover

On the other hand, all those who were caring for siblings had parents who were also providing care. Nevertheless, Simon saw himself as the primary caregiver for his brother, since his parents were working and he had always looked after his younger brothers. His situation seemed a little contradictory, because he said he had no choice and that it was not something he wanted to do, but he also said that if he had minded doing it, his family would have found a way to work around it. Beatrice was the youngest of six children, but saw her father and then herself as the main carers for her brother. However, she was the only child remaining at home with their parents when her brother returned from the hospital. Thus those who were present and available tended to have less choice in taking on the caring role.

Finally, Simon asserted that the reason he had taken on and continued in the role of caregiver for his brother was to help his family. This theme of choice in taking on the caregiver role is related to the questions of 'who is the primary carer?' and whether young carers feel free to move on to live their lives or feel constrained to be at home, which are discussed later in this chapter.

<u>What young carers found difficult about caregiving</u>

Some of the young carers found it difficult to deal with situations by themselves, without support. This included making decisions about leaving the person they were caring for to take some time for themselves or to lead their own lives, and dealing with emergency situations or other situations connected with the person's illness. In the latter case, sometimes the right decision could only be made after learning from experience.

"There's no clarity in terms of what to do, so doing things on the fly sometimes, it was difficult in that you didn't know what the consequences would be, just making rash judgements and decisions based on just gut instinct, that's what it was most of the time." Tarun

Tarun found it very difficult to find a balance between protecting his sister and controlling her, between being supportive and telling her what to do. Enid had struggled herself, and knew other people in similar situations, with the decision to send her mother to hospital when she was very ill, because she did not want to be the person who had done this.
Clover described the difficulty she had dealing with her mother's depression because she had no idea what was happening and it felt like there was nothing she could do to help. This resonated with the researcher's own experience, because as a child, it is very hard to watch your parent who is feeling very low or upset, and feel helpless and unable to do anything that will help. This was compared with being able to do something about it, for example, Mandy found it easier to help her brother when he was depressed in comparison with when he was psychotic.

"So that was quite hard to watch her be like that because there's nothing you can do to help, especially at that age, you've got no idea what's happening." Clover

Clover, whose parents had had depression one after the other, found it harder to find what would help her mother feel better. Whereas with her father they had been able to think of things to make him feel better, she found it more difficult to do the same for her mother. Clover's situation could be seen as illustrative of the individual nature of each caregiving experience, since she had found one situation more difficult than the other, in spite of both her parents having the same diagnosis (depression). It also highlights the different factors that contribute to the nature of a caregiving experience. When Clover's father was ill, both her mother and her brother shared in the caring responsibilities [see family protective circle]. She had been closer to her mother and found it harder when that relationship changed [see loss]. Clover also felt that her father's depression was less severe than her mother's.

AL: And what was that like for you 'cause your dad was ill but that hadn't affected you so much 'cause your mum had been looking after things, so was it very different when it was your mum who was ill rather than your dad?
Clover: Yeah. It's probably due to the role of the parents really 'cause I would say I was closer to my mum than I was to my dad because he worked and he was always quite a reserved person anyway, but then when she got ill I actually got closer to my dad because we had to kind of come together and try and look after her. So that was, yeah I think that was harder for me 'cause I didn't have her support, and especially doing your A levels and GCSEs it's like the hardest time in your childhood and you don't have your mum to help you, so that was quite tough.

<u>Understanding the experience of caregiving at a young age</u>
While four participants had parents who had been ill for almost all of the young carers' lives, in two cases they had little responsibility until their parents separated, and in two cases they lived with the well parent. However, the experience of Arthur, who cared for both his parents from the age of 6, helped to understand the particular circumstances of very young carers (under the age of 10 or 11). He explained that it was only as he got older that he became more aware of his mother's illness and understood it more. While previously he could tell that things were going wrong, he found it very confusing and difficult to understand why, for example, his mother would run away. Moreover, he

found it more difficult as he grew older and took on more of a caregiving role, before he finally got support through his school and the young carers' service.
Irene, who had lived with her well parent when she was younger, did not have caregiving responsibilities when she was very young but would visit her mother in hospital. However, she brought insight to this topic by highlighting the difference she felt when her mother fell ill again after a long period of being well. When her mother was ill when she was very young, she had nothing to compare it to, so the same sense of loss was not there then as it was later, when her mother became severely ill after Irene had had a chance to develop a deep relationship with her.

AL: So when you were small, you hadn't really been with her all that much but now when she fell ill in May last year, you'd had a chance to be with her and have a relationship with her and so on, so did that feel very different?
Irene: Yeah, completely. Total loss, it's almost like bereavement really.

Understanding the transitional stage of a young carer's experience

Participants described trying to move on from their role as a young carer, usually around the ages of 16-18. Some felt pressured to focus on the needs of the person with the illness, while they wanted a life for themselves as well, whereas Pauline felt she simply had to move away because she could not cope any longer, and described it as a relief to get away.
The issue was explored in depth with one participant, Arthur, whose experience with young carers' services and from meeting other young carers provided valuable insight, particularly on young carers' experiences of the transitional stage between school and adulthood. He felt that few young carers feel able to go on to University or to move away from home because they feel tied down by caring responsibilities. In his own case, for example, he was worried about how his parents would cope if he moved away and did not want to leave the safe environment of his young carers' group where he had been accepted and understood. It was not until he was supported by a tutor in thinking about University that he was able to explore it as an option. Similar feeling of restriction were seen in two other narratives

"So like there was someone actually from the young carers project where I live who was speaking to David Cameron, she says like 'I want to go to university but I can't because I can't leave my mum' and I think that's the issue which needs to really be addressed. In terms of how do you provide the support and make sure actually they feel like they can…"Arthur

AL: When you decided to go into work how did that happen?
Pauline: I had to work, we had no money. I was 16. We had, this is what I mean she's always blown money. I don't know how she spends it. I don't know what the bloody hell she spends the money on. But I just had to start working.

Participants sometimes found things difficult even after they moved away. Three young carers spoke of the guilt they felt at no longer being at home to look after the person with the mental illness. Clover described how she had not felt guilty about going to University but when, on a visit home, she found her mother after she had taken an overdose, Clover felt that she had broken free only temporarily.

"And it was really hard going from that situation where I was looking after her loads and then suddenly I was kind of breaking free and going to Uni and enjoying myself and then coming back and realising that she'd got really bad and I hadn't been there to help her." Clover

Pauline found it difficult to get used to a life of her own; she had been so used to her life revolving around her mother, with no chance to find out what she herself liked. Pauline and Tarun described it as trying to find a balance, between relief at getting out of the situation and guilt at letting the person down, and between dealing with difficult situations as a carer and trying to carry on with a normal student life.

"It was confusing and I did go through really weird, not like moods but like, it was so hard, on the one hand it's a relief to get out of there it really is. But then on the other hand I couldn't deal with feeling so guilty I felt like I'd let her down, like obviously I wasn't looking after her properly because I wasn't there anymore, and I did feel awful and it's trying to find the balance between." Pauline

Finally, Enid and Antonia mentioned the difficulties they faced in caring for somebody from a distance.

"This time when I wasn't there it was weird because I was very sad and worried about my mum, but not all the time because it wasn't there all the time, and actually I found that if I'd been with my mum the last sort of week when she was ill, I would have made sure she'd gone into hospital a lot sooner 'cause I think I would have been there dealing with it, and thinking 'This is awful, there's something that needs to be done now' whereas being far away it was like well, actually, maybe it's more than anything, it's just kind of embarrassing and difficult to deal with these things, and she's not going to hurt herself or do anything too stupid I don't think at the moment, so she'd probably just be fine rattling around in her house as long as she's got things to eat and that kind of thing, and so maybe it was a bit more relaxed about that I think just from being remote, but if I was there it would be incredibly alarming and I don't really know what to think about that, yet. I think that makes it more difficult." Enid

Cultural issues

While recruiting participants, it was felt to be important to have as diverse a sample as possible to get a range of perspectives on the topic, and particularly to include people from different minority ethnic groups. Five of the participants were from non-European ethnic communities and one had a mixed cultural background. Although participants were not asked to identify their ethnic backgrounds, some spoke spontaneously of their cultural background and its impact on their experiences, while with others for whom it might have had an impact, it was brought up by the researcher. The researcher herself is from a minority ethnic community.

For three of the participants, their cultural background had had an impact through the attitudes and beliefs of family members towards mental illness. This could be seen in their reaction to the illness, for example, in suggesting that the person with the illness was cursed.

"Especially, I'm sure you know as well, coming from an Asian family where mental illness or mental disorder has such big myths and superstition associated around it and it's, I mean I'm sure you know, it sometimes can be shameful for them, which I can still not understand why that is the case but obviously it's something to do with the tradition or the way they've been brought up." Abdul

It is notable that in spite of recognizing traditional beliefs and detaching himself from them, Abdul nonetheless described it as the "fate" of people with mental illnesses to be who they are, reflecting a fatalistic tendency that is traditionally Asian.

"I mean everyone hopes there's this miraculous cure, but really there isn't, is there? I mean, you can treat it and you can learn to live with it but can you really cure something like schizophrenia or psychosis? They are who they are and I suppose that's just their fate." Abdul

However, a cultural attitude did not necessitate a negative impact. Naima felt that a family-oriented culture was the reason for her mother's acceptance of her child's mental illness and her consequent caring responsibility.

"I wouldn't say that it's really, no I don't think it's had any impact on any of us looking after her. Maybe for my mum because where she grew up, just the country, it's very family orientated so it just helped her, that experience helped her to just take the changes in her child and just continue 'cause you can't change your family, so either you accept it or you are just going to drive yourself into insanity, so she just kind of took what was happening..." Naima

The influence of cultural background could be seen in the impact of family pressure on choices made and in the language barriers raised. Traditional family roles and pressure from the extended family to maintain the family reputation made it difficult for both Tarun and his mother to separate themselves from his father and make critical decisions for his sister's health.

"There's a lot of conflict of interest because obviously we grew up in an Asian family and I don't know if it's the same of all Asians but I know certainly in our family reputation is very important and keeping the family together is very important" Tarun

Additionally, the ethnic background of participants had a varied impact; for example, Rajini's grandparents' traditional beliefs made her feel different from other people and affected her social skills.

Thus, the ethnic background of the young carer did seem to influence the experience of looking after someone with a mental illness, although its role was smaller than was anticipated.

It's <u>mental</u> illness

This theme includes the differences highlighted between mental and physical illnesses, aspects of mental illness like being 'sectioned' and recovery, and the accompanying stigma and discrimination faced by participants and their family members.

Difference between caring for mental illness and physical illness

One of the questions raised after the first interview with a participant was whether young carers felt there was a difference between looking after someone with a mental illness and looking after someone with a physical illness. In the first interview, there were indications that there might be seen to be a difference with mental illness, which led to further exploration of this theme in later interviews, including clarifying whether it was in comparison with physical illness. .

Mandy suggested that mental illness was something that affected the whole family and needed to be seen that way. Other participants suggested that mental illness could have a big impact because it is less visible than a physical illness, that the impact was more likely to be emotional and that it could be very confusing for children. On the other hand, Antonia also pointed out that all children who have to look after parents lose something from their childhood.

> "And I think in that sense, it doesn't make a difference, but in the sense that it isn't a kind of physical and the emotion is I think more confusing, I think it's such a confusing illness for children to have to learn and understand, I think that's the only thing that would be a little bit hard to kind of, to have an understanding between two young people, one person who has to deal with a mental illness and one person who doesn't 'cause a mental illness is just so, it confuses you, you don't know what to feel because you're seeing that person and they can walk and they can talk and they can do whatever they can, but they're not the person you know and you love and they're behaving very unusually and sometimes quite scary and in that sense I think there is a difference in what you go through in terms of the different illnesses." Antonia

Participants also suggested that there might be better support in place for people with physical disabilities in comparison with mental illness, and that it might be harder to provide support for mental illnesses in the same way. For example, there tends to be less information available for mental illnesses.

> "I mean if you're physically ill there's NHS Direct, there's 999, there's the internet, there's walk-in centres, there's hospitals, there's A&E there's so much you can turn to if you're physically ill. I don't think there's enough information for people with mental illnesses in general" Simon

Arthur, who was caring for both a father with a physical illness and a mother with a combination of physical and mental illnesses, felt that caring for each of them had a very different impact since his mother's care was less regular and involved more emotional support. Participants felt there was a difference between mental and physical illnesses in terms of looking after the person; with mental illness, it is harder to know how the person is progressing or feeling, or how to deal with it.

"When someone has got a physical illness, like with her back you can see, physically see how she's doing. When you've got a broken arm you can see that it's healing, you can see when you're having good days, bad days. When it's mental you just don't know, there's no, because you can't see anything you don't know how she's feeling and then there's times she won't open up, she won't talk, there's times when she's so depressed and she's so out of it, upset and then she will all of a sudden break down and it's to do with something so stupid like M**** hasn't taken the rubbish out and you think are you seriously reacting like that over something so small, but you just don't know if it's normal." Pauline

"But yeah, I think there is a difference between somebody who has a disability that we can understand properly, say they can't use their legs or something. We understand that, and we know how to cope with that, and it's probably just as emotionally draining, but we know how to deal with it. With mental illness we don't know how to deal with it, and I think it's a lie to say that we do because we don't even know what drugs to give people." Mandy

One of the characteristics of mental illness highlighted by the participants was the sense of unpredictability that accompanies it. Part of this is due to the episodic or fluctuating nature of mental illness, which is accompanied by changes in the carer's role and perspective, as mentioned earlier, as well as changes in the relationship between the carer and the person with the illness. Part of the sense of unpredictability with mental illness is also due to the uncertainty involved in never knowing what is going to happen next, how the illness is going to change, or how the person with the illness is going to behave or react. Young carers described it as being constantly on edge, never able to relax, and found it difficult to get used to.

"Like, I mean even now to an extent she's that way. She likes to have you like, go shopping for her and, you know, and it's not, she's not in any way incapable anymore. I mean she was for a long time but now she's sort of more up, anyway, she does like to sort of say, 'Will you do this? Will you do that,?will you do this?' and I get really frustrated. 'Cause I know, she never used to be that way, so much. So I get really impatient. And it's hard, because, when she is ill in hospital and had like, really low self-esteem, you know you feel sorry for someone when they feel that way and you want to make them feel better. And so, I would be quite sad for her, during that time. But now I don't have those sort of emotional emotions about it, I just feel angrier now." Irene

"But it was difficult to understand like the whole, 'cause obviously it would be one day she would be fine, it's not like it's a constant thing, there'd be very much up and she'd be fine for a month or two and then she would really just plummet and she'd back in to the mental hospital and sectioned. I found it quite difficult to get used to that sort of sense of uncertainty that one minute she'll be totally fine and next minute she'd be rushed straight back in again." Arthur

Arthur suggested that with mental illness there might be a greater chance of single parenting because of broken relationships, and this might mean that young carers looking after a parent with mental illness were more likely to be sole carers [see theme of sole caring discussed later].

Being 'sectioned'

This theme explores the issue of family members being detained or 'sectioned' under the Mental Health Act[12] in the context of the young carer's experience. In addition to texts that had been coded under this theme in the first instance, a query was run in NVivo to find all references to sectioning, and only those that added to the understanding of the young carer's experience have been detailed below.

Arthur found his mother being sectioned difficult to explain to his friends. He himself had only understood what was happening, and realised that it was for his mother's safety, when he grew older. He also found that there were very few young people who had had that experience, making it difficult to find other people with whom he could talk about it. However, he also described it as a "sense of release" in comparison with being constantly on edge in anticipation of what his mother might do when she was feeling down.

> "...but I think in a way it probably sounds a bit weird but when she was sectioned I knew that, it was almost a sense of release in comparison to what she, that sense of living on the edge, so is she going to try and run away because you can sense when she's getting more and more down, she becomes more withdrawn, she would be sleeping in all the day, would stop doing things, you could tell just by the tone of her voice that she was heading downwards in terms of her mental well being. And it was that sort of dealing with "OK where is my mum?" and this is like 2 o'clock in the morning, having to get the police out to look for her and things like that, that was probably the most difficult, I think that's possibly even more difficult than accepting the fact that she had been sectioned." Arthur

Enid felt that it was preferable to try to get help for her mother (i.e. get her the hospital care she needed) before it got to the point where she had to be sectioned. The problem was in knowing who to call for help in mental health services, particularly when her mother had been out of the care of services for a period.

> "And I think the thing is as well that, maybe because I didn't know who to call because I don't feel like the route that I should take is to have to call the police to get her sectioned, and I've never done that and I think it's just ridiculous that that's what you need to do. And I would just bug psychiatrists until they do something because I just think that's, I think it's a really bad way that it's organised, and I don't know why you would want to call a policeman to come and deal with somebody who is mentally ill." Enid

Tarun highlighted the difficulty he had with getting help for his sister who was harming herself by abusing aerosols.

> "I mean the mental health service was a no go area purely because they will only treat people if one is willing to be treated, and that's unless they are sectioned under the mental health act which she wasn't. She couldn't be sectioned under the mental health act because she wasn't causing any harm to anybody else and she was complying with treatment apparently, so it was a lot of bureaucracy involved there." Tarun

Antonia felt the weight of her responsibility as next of kin for her father, particularly in relation to his detention, since she had to agree to him being sectioned and was the one who could get him out of hospital. She highlighted the difference in the experience

[12] References to the Mental Health Act denote the Mental Health Act 1983

when there was somebody to explain the process clearly to her and to keep her informed.

Finally, Huy described himself as being aware of psychiatrists and their role, including in sectioning a person, but his situation was unique and will be discussed further under the theme 'crisis point'.

Crisis point

With mental illness, the situation often reached a crisis point for the ill person or the young carer when it was realised they needed help. While Mandy's brother had been detained under the Mental Health Act at other points in his illness, the situation reached a crisis point at home when Mandy wanted to leave home because she could no longer be around her brother, and her mother had to call the doctor to get help for her brother. In three cases, the crisis point was when their siblings were going to hurt themselves or somebody else (e.g. Tarun's sister had taken an overdose). Abdul's family realised that his brother had a mental illness when he was 'sectioned', when they realised it was more than just learning difficulties or delinquency.

Sometimes the young carer went through a crisis point. Pauline realised she could no longer cope with her mother, to the point where she was self harming, and had to leave home to stay with her father for a while. For Arthur, the final straw came when his school showed a complete lack of understanding after a long night in which both parents had been taken to hospital. He walked out of school and refused to go back because it was too much for him, which was when the school realised that he needed help.

Huy and his mother had separate crisis points. He described the point at which he could no longer cope with the situation. Whether he was actually detained under the Mental Health Act is unclear. While he was receiving treatment from the psychiatrist, the physical abuse from his mother got to the point after which he had to tell somebody and she was 'sectioned' and Huy was sent into the care of his aunt.

> AL: Did anybody sort of explain, did you know at that time that it was a mental illness, before she was sectioned?
> Huy: I think I already knew because I was, I think when I was 14 there was a time when I just really really hated the house because there was nothing to do and the living conditions and I really really went mad, and I actually caused noise and the police come around. My mum wasn't there though, my mum was outside shopping and I was like oh my god I couldn't handle, not in some sort of I'm going to do suicide, no, nothing like that, I hadn't thought about, it's just like oh my brain hurts. And then the police came around and mum eventually went home and I just immediately told the police that I needed to see a psychiatrist right away and eventually they made arrangements, I had to see my psychiatrist.

While other illnesses can also develop insidiously, with mental illness it is not uncommon for a crisis to be the only way to find help, either for the person with the illness or the person caring for them.

Recovery

This theme draws together participants' perceptions of recovery, from a belief that the person would or could make a full recovery to despondence about the prognosis of the illness. Two participants from minority ethnic communities saw mental illness as something that could be treated but could not be cured. Irene's perception of her mother's recovery changed from hope to hopelessness to recognizing that one had to

learn to live with it. Most of the young carers had come to realise that recovery is a long process.

> "I'm worried that she's going to get so ill and so depressed that she's not going to be able to function at all like a normal person and if that happens I would just, I don't see no point in my living to be honest if that happened, yeah I couldn't deal with it at all." Rajini

> "So, it seems to me that…that probably she'll never be like she was again. And it's just the best you can make of it with – with the illness and with the medicine." Irene

> "Like with a physical illness you can see it, well it might not come but at least you know, like if you break your leg you know 'Right, well I've got a plan', but I think with mental illnesses it's something completely different, and it's never something you get over because it's obviously going to keep coming back, it's going to have little triggers and it's almost trying to avoid those triggers so it doesn't happen" Clover

Antonia highlighted the fact that the episodic nature of the illness can make the recovery process emotionally very difficult.

> "And so you feel like you've conquered it you know, you feel like you've got over an episode and you can go back to building on a relationship which is with that person, and then it will happen again and you'll have to go through losing the person you care about and dealing with this nightmare of a person, and it's really conflicting emotions…"Antonia

Two other participants stressed the importance of care after hospitalisation, with Abdul suggesting that educating the family about the illness and recovery along with better integration of the roles that family and services play could help with rehabilitation and recovery.

> Abdul: …it's getting like we were saying, maybe introducing, trying to get people that understand the culture and talking to them, telling them, explaining to them what it is, how you can live with it, what you can do to enhance the recovery...
> AL: Ok.
> Abdul: ...play a role in the rehabilitation process, not fully rely on the psychiatrists or the doctors working in the hospital to give them medication, to transform his life 'cause that's not going to, I don't think that's going to work, it has to be everybody in the equation that will contribute equally.

Stigma and discrimination

The stigma and discrimination associated with mental illness was evident throughout the data. A lack of understanding and the rarity of severe mental illness can result in myths and assumptions being made. Naima felt she had been stigmatized at school because of her sister's illness and had not been able to bring friends home. She had had to change schools. Beatrice found that her friends were scared to come around to her house because of her brother's illness. She, on the other hand, just found it strange that her friends were so afraid of her brother.

"Because there's a stigma with mental illness that hasn't really gone, even to this day it's still the same, 'Oh she's got a mental illness', 'Ohhh *scary voice* don't talk to the nutter kind of thing'." Naima

"And then there'd be the other thing, like most of my friends knew that he was ill but didn't really like, everybody that doesn't know anything about schizophrenia thinks that they're going to stab them all the time or something, and so my friends were always really scared about coming round my house. And like they'd always like ask me if he was going to come into our room in the middle of the night and attack us, and I'd be like "Why would he do that?" That was really difficult because of the stigma attached to it, and people wouldn't come round." Beatrice

Young carers found it difficult to talk to other people outside their families about their experiences and about mental illness. While Irene and Rajini felt they could discuss their situation with friends to some extent, and for Simon it had never been a secret (albeit after an initial urge to conceal the illness on his parents' part), three others felt it was not something they could share with their friends and Naima described her family's attempts to conceal her sister's illness from other people to protect her. Antonia described it as living a double life, because her friends were unaware that her father had schizophrenia and while her teachers knew, they would never talk about it with her, making her home and school lives very disparate.

"And it wasn't really talked about that much 'cause where I grew up in C**** there's no such thing as kind of talking about, like none of my friends knew, it was almost like a secret..." Antonia

"Maybe socially there was problems because you know, your social life does stop because we couldn't have people over for dinner or whatever any more, because they're gonna see her, they're gonna see what we're trying to keep under wraps kind of thing." Naima

Clover, who had a friend whose father was manic depressive, felt that depression as an illness was harder to understand, especially when it was difficult to find a reason for the person's illness.

"...and she just didn't understand why my mum was ill because my mum has got, you know, she's got a loving husband and she's got kids who are doing well at school and they weren't financially in trouble or anything like that so yeah, I didn't really get the support in that sense and I almost felt guilty for having a mum who was ill but with no reason for it so to speak, like physical reason." Clover

For this reason, young carers found it difficult to explain particular aspects of mental illness to other people, such as the emotional strain of the situation, strange behaviour by the person with the illness, and sectioning. For example, Antonia described it as being easier to say her father was on drugs than to talk about his mental illness.

"...so that really helped having my friends to support me, but the thing is they didn't know what it was like for me to kind of have this problem, although they were helping me they couldn't really kind of have helped me through the emotional side of it all because they didn't know what it was like." Clover

In contrast to this, participants also described how they felt being with people with similar experiences, who could understand what they were going through.

Naima: And when I transferred high school it was yeah, I would bring friends occasionally but lucky for me one of my friends had a cousin with Down's Syndrome, the other had a brother with autism so we kind of, it was kind of easier, I didn't have to explain so much to them because they just got it, it was just so refreshing to just have that change.
AL: And they knew a bit about what it was like?
Naima: Yeah they knew all the ins and outs of it and how no day is the same. One day you might be fine and the next day all hell's broken loose, yeah, they were understanding of the situation.

Beatrice had faced discrimination: people had tried unsuccessfully to bully her, and a friend's mother did not want her friend to have anything to do with her. Some of the family members who were ill had faced stigma and discrimination as well, which made the young carers feel protective of them. Beatrice highlighted the irony in the fact that stigma is often based on assumptions; for example, people who knew that one of her brothers had a mental illness often identified the wrong one.
Finally, Enid pointed out that existing procedures to help people with mental illnesses can be unhelpful for tackling stigma and discrimination.

"...I think it's a really bad way that it's organised, and I don't know why you would want to call a policeman to come and deal with somebody who is mentally ill. And like this time when my mum was ill they took her, there wasn't any room at the local hospital, they took her to D*** which is about a half an hour drive a way in the back of a police van with police men and it's like well that's not the way it should be, this is sending out very odd messages about what it is to have a mental illness if, when somebody is being seriously mentally ill you call the police and not a medical professional" Enid

Understanding mental illness

The researcher explored the extent and sources of young carers' understanding of mental illness. This theme includes information on the mental illness, and the need for information in general is further expanded in other themes.
Initially, the majority of the participants knew little about mental illness and did not understand what was happening or that it was a mental illness. Beatrice and Arthur described themselves as feeling confused, especially when Arthur was younger.

AL: What did you understand about what was happening 'cause you were really young at that point?
Arthur: At the time not a huge amount, all I realised was that my mum every so often would go away, potentially sometimes for a few weeks at a time and you could tell there was things going wrong, so for example at like her lowest points, I was probably around 10 or 11, she would try and run away sort of thing if she was in the mental hospital like and wasn't sectioned, there was a couple of times that she ran away from there. And so it was quite confusing for me at the time, it was only as I started to get slightly older that I started to realise the reasons behind her mental health illness and you could start seeing the triggers and things there.

Thus their initial responses to a family member's illness reflected their limited understanding of mental illness. Mandy thought it was normal for brothers and sisters to hate each other, when her brother began to be antisocial, while Naima wished her sister would just be normal instead of behaving so differently from everybody else. Antonia described herself as being scared and fascinated by the difference in her father. The exception was Huy; both he and his mother had been treated for OCD and he stated that he knew that it was a mental illness and that he was already aware of psychiatrists and their role when he saw a psychiatrist. He also felt that his own illness had helped him to understand his mother's illness.

AL: How did you know about psychiatrists if you don't mind my asking, as in that for starters that they existed and so on, because you were 14 or 15.
Huy: I don't know. I don't know how I got knowledge of that particular section role, I dunno, probably through school or television or something, that psychiatrists are there to help you if you have a mental health or if you have any particular issue that is affecting your lifestyle or something like that so yeah, that's how I, I already knew that psychiatrists exist and I told the police, please see a psychiatrist because they are able to understand what things that I am going through.

Young carers had a variety of perceptions about the causes of mental illness including: feeling that problems during foetal and early development might have caused the mental illness, or that an aunt with a mental illness might have been a negative influence on a younger brother's illness, and more than one felt that drugs were the trigger for the illness. Their perceptions extended beyond surmising about causes to speculating about behaviour: Pauline felt that her mother was mostly seeking attention, and she was unsure whether her mother's illness was the reason she had to do all the housework or whether her mother had just been using her, because it was later shown that she was capable of doing it herself. Irene wondered about the relationship she had shared with her mother in the time that she had been well: was that her mother or was she just a 'product of medications'?
With little knowledge of the illness, Rajini was afraid of what would happen if her mother's depression became much worse.

Rajini: I don't know what happens to people who have really really severe depression when they're in in hospital, I don't know, I can only imagine that what happened where they don't want to speak to people or they're just so ill that their brain doesn't function properly. I don't know what would happen if that happened.
AL: Have you ever had any information about how severe your mum's illness is?
Rajini: No. All I know is that she takes the maximum dosage on her anti-depressants, maximum possible dosage.

These quotes suggest that more awareness in the general population and understanding of mental illness in family members could be helpful in reducing the distress from uncertainty and expectations in patients and carers. For example, Abdul highlighted the fact that, without an understanding of mental illness, there can be pressure from other people for the ill person to be 'normal'.

"And it's also difficult sometimes, when my brother sometimes phones and you can tell he is either very slow in speaking or he is very upset, and I can hear like my family members speaking on the phone saying "Oh why you talking like this for?", "speak normally!" and this and that. And it's not nice because sometimes I think I wish they could understand more about what a mental illness is like, because it's something you have, the way I see it is you have it so you have to learn to kind of live with it and not really say "Oh, are you going better?" because what do you expect?" Abdul

The level of understanding may depend on the young carer's age, and including the young person in the family member's treatment could help with understanding. Recognition of mental illness can also depend on the type of illness, since the onset of psychotic symptoms can be a major change and can make the recognition of severe mental illness unavoidable.

"She was trying her best to calm her down and get my sister to see that you know, you can't beat somebody up just 'cause you feel like it or you can't hurt someone just because you want to. Then she kind of understood that you can't reason with this, you can reason with one in their right mind but she was not in her right mind, so my mum had stopped trying to reason with her and just decided treatment is the only answer." Naima

While a young person might not understand what is happening, they can still see that something is wrong and that there is a change in their family member, and find their own ways to describe it. They also recognised that different illnesses can express themselves in different ways.

"I remember talking to my mum about it as well. Like obviously I didn't know what was wrong, it was just like there's something wrong with him, what's wrong with him, where has he gone, that's the way I sort of explained it, it was like he wasn't there anymore." Beatrice

Thus, would explaining the nature of the illness to young carers help and, if so, how could this best be done? Naima pointed out that a mental illness was something that needed to be understood, and just being given a 'factsheet' was not enough. Tarun, on the other hand, felt that first hand experience was more useful than providing information about the illness. He also highlighted a problem where too little knowledge could be a bad thing, because he had found himself making assumptions based on the

little information he had. Irene had believed that her mother had completely recovered from her illness and felt that there was nothing that anybody could have told her about the illness that would have prepared her for her mother falling severely ill again.

Tarun: I think knowledge is important but also experience at the same time, so someone who knows about these things would have been…
AL: Somebody you could talk to rather than having information...?
Tarun: Yeah, I could have been an expert but I still would have made a wrong call, I didn't have any experience dealing with mental health people, I really didn't, so even if I had the information right there and then it wouldn't have been the ideal solution.

"The doctors, obviously they just told us that, you know, she's schizophrenic, but I felt almost to them that it was just a word that they'd just said but that one word that they'd just said it changed my whole life, so I need to understand that better than the fact sheet you're giving me kind of thing." Naima

This was supported by other participants whose previous experience with mental illness had been helpful for their understanding of their family member's mental illness.

"But I don't ever remember feeling, after he went to hospital I don't ever, obviously before he went I was confused about what was going on, but after he went to hospital I don't remember feeling confused about what was going on. I knew that he was ill and I got that. I guess because I'd been to the psychiatric hospital with my sister, it was kind of like normal because I knew the way people were like when they were ill, so I just saw it as he's ill." Beatrice

AL: But then how much did you know about mental illness at that time?
Naima: Nothing at the time, just what you see on TV, I had no experience of it, I had no first hand contact of anybody that had a mental illness so.

Naima and Abdul mentioned that their prior knowledge had come from media portrayals. After the mental illness was recognised, several young carers said they got more information on the illness from mental health professionals or by looking it up themselves (by reading or on the internet). Since caregiving could be a process of learning (see young carers' descriptions of the experience), for some of the young carers their understanding of the mental illness came through the experience of looking after the person. For others, it came through working with mental illness or through studying about it.

"And I didn't know anything about it, everything I saw from experience, I saw how my sister behaved as a result, what her triggers were, things like that. And they kind of, I adjusted my role accordingly, I changed my approach you know, as I learnt more and more about my sister, but I didn't know anything, I was only 13, I didn't know what the hell was going on." Tarun

Discussing mental illness within the family

In addition to talking to other people outside the family about the mental illness [see stigma and discrimination theme], one of the themes identified in the transcripts was discussing the illness within the family. While in some families the illness was never proactively talked about, e.g. because it was so difficult, Antonia's mother explained to

her at an appropriate point that her father had schizophrenia. Talking to the person with the illness about the illness could also be difficult, if they did not want to talk about it. One sibling's anxiety about his illness meant that any discussion about it was unidirectional; Mandy was careful not to talk to her brother about something that might upset him.

> "It's not anything that was ever sort of proactively talked about, it was like everyone knew what was going on but no one ever really spoke about it." Beatrice

Initially from the interviews it seemed that recognition of severe mental illness was unavoidable and therefore easier to discuss, but conflicting accounts suggested that this was counteracted by people's reluctance to accept that a family member might be severely mentally ill.

> "I think with my brother because it was far more severe it was a lot easier to talk about it because he was sectioned for a long time and so... whereas my mum she's been able to cope with it somehow." Mandy, comparing brother's schizophrenia with mother's depression on the topic of discussing her mother's depression with her.

> "Yeah obviously I was so young, I don't really remember, but I guess from what she [older sister] said sort of now is she sort of thought from the way he was behaving she thought that he had schizophrenia and she sort of said that to my mum and my mum went completely mental at her and, like I said, we didn't speak to her for about 2-3 years after that. I mean I saw her if I was at my Nana's or something like that and my sister also tried to speak to my Nana about it because my Nana was a psychiatric nurse back in the day. My Nana didn't get angry about it but she didn't agree with her either." Beatrice, whose older sister first thought that her brother might have schizophrenia.

Thus, even within the intimacy of a family unit, talking about mental illness can be difficult.

Impact of caregiving on young carers' lives

The impact of caregiving could be seen in different aspects of a young carer's life, including their education, career, social lives, social skills, relationships and mental health. The impact of caregiving on everyday life and the emotional impact could also be seen.

Impact on education and work

For some young carers, looking after someone with a mental illness had an impact on their education, because they missed school or found it difficult to work at home. It could have a disruptive effect when, for example, young carers had to deal with crises in the middle of examinations. However, there were exceptions: Mandy saw that as part of life - there are always things that take up time. For Rajini, studies were the one thing she had apart from her mother and it was, in a way, a coping mechanism, something different on which she could focus. Clover said she worked harder because she saw it as something that could make her mother feel better.

AL: When you'd missed a lot of school and stuff, what was that like for you?
Pauline: It was hard. It was really hard, I never had time to do homework. But it wasn't like I didn't want to go to school, my mum would say things like I'd get up and I'd be trying to get ready for school, she'd go "Oh, don't go into school today, stay off and we can sit and watch a film together" or "we can do this", or "I need help with that". And then if you still say no, then she starts crying and, and she just knew how to play me, she still does. To an extent she still knows how to get me. And so I'd stay off and she'd phone up and say I was ill, or, she's always been kind of manipulating like that.

Young carers found it difficult to explain their situation to people at school, whether peers or teachers, and sometimes found themselves stigmatized at school. Some participants had been bullied at school, though not necessarily as a direct result of caregiving. Things could be made easier, on the other hand, when a school understood the situation and tried to help (see *What can schools do?*).

AL: And how is that for you when you're in school and high school and trying to go to university and so on?
Naima: Because like I changed high school when I was 14, because I don't know I'd just kind of had enough of being labelled as the nutter's sister kind of things, 'cause kids can be cruel, they have no understanding of anything so I just didn't want to be at that school anymore, so I transferred to another school in the area and yeah, it was good...

In some cases there was an impact on their work, for example, finding it difficult to do a job properly because of the distraction.

"And I think, although that distracted me from a lot of other important things in terms of my career and I really didn't care about the things that were important. I ignored some other important things which were my career, my grades and things like that, I let them slip and I think, not to say my sister was at fault there, just to say I thought my sister was more important, I thought my family situation was more important." Tarun

Impact on social lives, skills and relationships

Caregiving could have an impact on young carers' social skills, social lives and relationships. Two of the young carers reported feeling different from other people and two felt that their experiences had had an effect on their relationships with other people.

"I can read people in that I can see if they're being truthful to me, but then at the same time it affects my ability to trust people, I don't trust anybody. So you know, it's certainly affected my relationship with family. If any of my cousins or uncles or anyone says anything I was like 'what about this?' and 'what about that?' and I always end up making them into a liar. I mean people lie all the time and I know that, white lies are harmless but if anybody tells a white lie, I almost try to interrogate them until they admit that they've lied so it does affect my relationships, it does, I'm very distrustful, I don't trust anybody in that way." Tarun

6 out of the 14 young carers reported an impact on their social lives as a result of their experience. Five of them were limited in different ways in their ability to go out and

socialize with their peers, either because of their caregiving responsibilities or because of the family member's illness.

AL: Do you get a chance to hang out with your mates and so on?
Simon: Well, to be honest, not so much, because when he started first getting ill I couldn't see them that much and then they went off to university. And because I'm home all the time, because I was home and because I don't have a job and because I don't go to school or university, I haven't had a chance to make new friends, so there's not much of a social life there anyway. But before like I said when I still did, before my friends went to university, a lot of the time I couldn't because I had to stay and care for him. So it definitely has an effect, yeah.

Two young carers felt that they had not developed normal social skills because their parents' illnesses meant that they had been very isolated. For example, Rajini felt that it would be helpful to have outside interests given her caring responsibilities but, feeling different from other people because of her experiences and lacking the confidence to make new friends easily, she felt caught in a cycle of isolation. In her case, there were cultural issues that had also impacted on her social skills.

"But I think it's sort of a cycle because I was with my mum so much when I was little so because of that I never went out, I didn't make any friends, and my mum didn't socialise with anyone and a lot of people, I mean people I knew back at school who had big social circles it was because when they were young their parents went to parties or took their kids along or socialised, so on and so on, but my mum never did anything and my grandma and grandpa were sort of like you know girls shouldn't speak to anyone, that sort of thing." Rajini

Impact on young carer's mental health

Participants expressed concerns about their own mental health. Huy was seeing a psychiatrist for what he called his OCD, another had harmed herself for some years and had been on antidepressants until she decided that she did not want to end up like her mother, and two mentioned their own depression.

AL: Do you think it's had an effect health wise dealing with so much and being so stressed?
Clover: No I don't think I've had... what on my health? No, I don't think it's ever made me ill, not physically, perhaps emotionally ill. Yeah, I have been Ok really, I've never really had much illness really in me, it's almost made me stronger. I look at her and I think 'Well I will make sure I never get like that'. Or at least I try to, this time it's been quite hard, I think I have been probably depressed for, I was, I'd say for about a month. Not, obviously not as bad as her, I wouldn't class it as the same thing, but there were times when I just couldn't get out of the house or anything like that. But then I'd been be looking at myself and like 'No, you're looking like your mum, stop that, get a grip of yourself'. So I actually think I'm a little bit different from her in a way, 'cause I can actually tell myself to not be ill, but it's an uncontrollable thing I guess.

Arthur, who had been very involved with young carer groups and representing young carers, emphasised the psychological impact that could result from caring and highlighted the importance of mental health awareness, not only for young people with mental health issues but also young people looking after someone with a mental illness,

in order to support them, especially since mental health problems (for both carer and person cared for) could be hidden.

> "I think so yeah, not just for in terms of caring for people with mental but in terms of I don't know it seems to be a growing problem with young people having issues with mental health issues, and like caring for someone with a mental health issue isn't always apparent, so for example there were a lot of young carers, people in my group who did get registered with depression because the effect of caring for someone... ?? parent then all of a sudden you've got a dual burden of care, so caring for a parent with physical disability and then caring for a sibling who's suffering from depression." Arthur

Everyday impact

The difficulties with balancing normal activities and caregiving, the restriction on freedom and the isolation all had an impact on everyday life.

Problems with finances and benefits

Some of the young carers mentioned the difficulties they faced with finances and with benefits, and the impact that it had on them. This theme was linked to the person with the illness, because three mothers had difficulties budgeting and managing money, and Irene's mother got into trouble about her benefits. The first three mothers would spend money regardless, which resulted in two of them spending their children's money. This meant that Pauline and Rajini had little control over their own money.

> "...but it's only I think since she got ill she cannot deal with it, she just spends it like she's just living in the present without thinking that tomorrow's going to come so I just said to her, I did actually say to her, 'this year I want to have complete access to my account, I don't want you to take any money out'. And then at first she said 'yes', but then she's just been ignoring me so but I just thought, no, there's no point arguing about it any more I guess. There's nothing to do about it." Rajini

This had an impact on the young carers. Rajini felt angry about this and worried about paying back her loan. The financial issue was emotionally difficult for her and induced a feeling of hopelessness. Pauline had to start working at 16 because there was no money and her mother's tendency to borrow from her continued to make things difficult even after Pauline moved away from home. Huy's mother's difficulty with budgeting meant that both of them struggled when the money ran out. It also could have an effect on the person with the illness, e.g. Rajini's mother's difficulties with money were detrimental to her own mental health and Irene's mother's became ill again with the financial stress.

On a different note, Simon could not get Carer's benefit because his brother was not classified as disabled while Naima's mother had to give up work for full-time caregiving.

Emotional impact of caregiving

Emotions like anger, sadness, fear, guilt, frustration and disappointment as a result of caregiving, blame, and the stressful nature of caregiving characterise the emotional impact of caregiving.

"I think it was because he wasn't there, like he wasn't my dad, he was this freak that I didn't know, and I was angry at that person and I wanted him to go and I wanted my real dad back, and I think I was angry because I couldn't do anything about it, it's not like a physical illness where if you take the medication then you know you'll see an improvement, like it took so long." Antonia

Young carers felt frustrated by the patient's behaviour, by mental health services, when they did not understand what was happening or what they should be doing to help. There were also feelings of guilt, particularly at moving away from home and moving on with life. Guilt was frequently linked with blame (see below).

"She gets quite messy when she's ill, when she's like manic. I remember the house used to be just very, just stuff everywhere. And I used to hate that when I was like 14 or 15 like, quite like, a teenage angst as well, I used to get really frustrated about that. And I am like it now a bit, but I can tell her more in, like less than an angry way, you know. 'Can you like, try to keep the house tidier..' " Irene

"...so I think a lot of the decisions I made were done properly but I think there's a lot of guilt there to be honest, but whilst I was doing it I didn't panic I mean it wasn't a question of me ever feeling fed up or anything, I just knew it had to be done. But as I say, all in hindsight it does come back to me and I think maybe I should have done that, maybe I shouldn't have done that, and that often goes through my head even now." Tarun

Young carers blamed themselves for different reasons: Huy and Rajini felt that the illness was their fault, Mandy blamed herself for not recognizing that her brother had a mental illness, and Rajini was angry with herself for allowing the illness and her cultural background to affect her chances in life.

"I was abused by my mum's boyfriend and that was really hard on her, she couldn't cope with it, so she fell ill." Rajini

The stressful nature of the experience was frequently mentioned, with one of the main reasons being their concern that the person they cared for could be a threat to himself/ herself or others. Young carers described it as being constantly on edge, worrying about what might happen. This was in addition to the normal stressors of youth, like doing school examinations or going to University. Antonia had the pressure of being formally named next of kin when her older sister moved to another country, while she was still at University.

"Like I said the main thing is its stressful 'cause you never know what he's going to do, you can't even take a nap, you go to wake him up in the morning and you think is this the day when I find him and he's gone all the way so it's very stressful" Simon

"And I think I now understand the limits of what my mum would do more as well, I think before I was much more worried about what might happen rather than what was actually happening." Enid

Impact on physical health

In one case (Pauline) there was also an impact on physical health when she began to develop stress-related migraines.

"That's what I mean, I got to a point where my migraines were seriously 3-4 times a week. I was getting serious migraines where I couldn't get out of bed properly and I was throwing up and I was just so worn out, I was exhausted, physically, mentally drained, I couldn't take it any more." Pauline

Distress

The term 'distress' was only used spontaneously by two participants; neither use of the term was directly in relation to the young carer's experience. During the initial coding, the researcher identified some data segments as being indicative of distress, using her construction of the term by its dictionary meaning of 'extreme anxiety, sorrow, or pain' (Oxford Dictionaries). The aim was also to inductively construct the meaning of the term from the data. However, this was difficult since the context for each coded text varied greatly. Some of the distress coded was as a result of physical abuse (one participant), or feeling threatened or scared by the ill person's behaviour (four participants). Other codes were not as clearly linked: distress was identified in Rajini's worry about losing her mother to the illness, in Irene's childhood memories of visiting her mother in hospital and her description of repeatedly finding her mother after an overdose, and at the crisis point of Huy's own mental illness.

"It was either that time or it would be another time but I'd gone back home anyway, and she had taken another overdose. So, like, it was all just like, the sort of thing that I would prefer, prefer the professionals not to allow to happen. So, it was three times in total that I found my mum after taking an overdose." Irene

"... so it was sort of happiness as well at the time but I was suffering..." Ranjini

AL: And you said that you didn't want to go back to, oh no, you said the wards reminded you of childhood. Did you mean that your mum had been in a psychiatric hospital when you were small and you had gone to visit her?
Irene: Yeah, so my dad would take me and my brother, I guess every week to see her. I was just like, it's just not a nice way to spend time with your mum, you know, when people in there are all sort of unwell. I'd just cry every time I left like clockwork, walk out crying...I just hated it.

Simon, on being asked directly about distress and its applicability to his experience, connected distress to the feeling of being constantly on edge described previously, not knowing what might happen or what the ill person might do. He also related distress to the young carer's concern that the ill person could be a threat to himself/herself or to others. His response provided some insight into the construct of distress in the experience of young carers, since the feeling of being constantly on edge and being concerned that the ill person might hurt himself/herself or somebody else were strong themes that were identified in several interviews.

AL: Do you think the term distress applies to your experience?
Simon: Yeah, definitely I think so, yeah.
AL: And you found it distressing?
Simon: Yeah
AL: How? Or, as in, this is probably going over some things we've discussed again, but how do you feel it was distressing?
Simon: Just the constant, not necessarily fear, but always thinking 'What's he going to do next?' and 'What if he does something really major'? It was never so much the fear of him hurting other people because it wasn't part of the pattern, but what if in one of his blackouts he accidentally cut himself too deep and that's it, what kind of effect would it have on my family?

Loss

There was a feeling of loss throughout the interviews, for different reasons. Most of the participants described having lost something during the experience, for example, losing the family unit when parents split up, losing a home, losing a sense of stability, losing parental support.

"It was a huge adjustment, should I say, 'cause when my dad left we kind of went from living in a big house with no worries, going to a good school with, it was the perfect life. Then he left and suddenly we had to downsize our house 'cause, you know, my mum couldn't live there any more and then my sister wasn't well, then she stopped working and it was like, so now we've got less money coming in, it was just a rolling thing of, you know, from bad to worse and I just couldn't understand it. I just couldn't understand how in the space of a few years I'd gone from here to so far over there." Naima

"She's been ill for all of her life, in and out of hospital, but for my life I only recall her being ill up until I was about 10. And then it was obviously not completely stable, and it was stable for me until my mum's, for the last I'm going to say 6 years, until last year." Irene

Loss was not necessarily related to the mental illness, unless the illness had been part of the reason for the family breaking up, but it was a noticeable theme. Antonia described the experience of caring for a parent as losing something from one's childhood.

"...in that sense you know all kids that have to look after parents have to go through that, the loss of kind of, you feel like, you know, you don't, you lose something from your childhood by having that, having to go through that." Antonia

Most notable, though, was the loss of the relationship that had existed previously with the ill person, and the feeling of having lost the person to the illness, which occurred in more than half of the narratives. This was not necessarily a permanent state of affairs and the relationship could return between episodes or when a family member recovered, but it also meant that loss could be cyclical and repeated, which again could be difficult for the young carer. They described it as the person they knew not being there anymore. Antonia portrayed the change as scary to watch, yet fascinating, while Irene compared it to bereavement.

"And because M*** [her sister] didn't really know dad like I knew dad, it almost as though she wasn't as affected because she didn't see the huge personality change because she was never really close to him anyway, so she just realised that he was weird, that he had changed and he was weird, but she didn't have a strong relationship with him so she didn't kind of sense that loss that I felt, like I'd lost my father, and I think that was the hardest thing." Antonia

"I remember talking to my mum about it as well. Like obviously I didn't know what was wrong, it was just like there's something wrong with him, what's wrong with him, where has he gone, that's the way I sort of explained it, it was like he wasn't there anymore." Beatrice

What was important, as Irene pointed out, was knowing the difference: if they had had a chance to know the family member when he/she was well, then they knew the difference when the person became ill and could feel the loss.

"In a way…yeah, yeah...my situation – it's unfortunate that my mum was so well, because then I – I knew the difference. That was what was so sad. Because I knew what she was like, and had, you know, become close to however she was." Irene

Some of the young women taking part described the loss of the mother-daughter relationship (although there were also young women who were, in their words, 'daddy's girls') as the loss of a special bond. Clover, comparing her experience of her father's depression with that of her mother's depression, felt that losing her mother was harder because she was closer to her, although caring for her mother did bring her and her father closer together. Even Antonia, who shared a close relationship with her father, felt that it must be harder to lose a mother to the illness.

"So it's very upsetting when she's ill and she's not herself, and I think part of it as well, I have a very good relationship with my mum but when she's ill it's like she's gone on holiday for 3 months or something, and actually you need your mum and if she's not being your mum then that's not nice 'cause you think 'Well this isn't right, I should be calling you up and telling you mundane things about my day and you'll be deeply interested and not telling me to shut up and not call you, that', that it's difficult." Enid

Positive impact of caregiving

It is important to note that looking after a loved one with a mental illness does not inevitably have a negative impact; there are also positive aspects. The first of these was the strengthening effect on relationships. Clover and Tarun described the closer relationship they shared with the person they cared for as a result of the illness. Clover also highlighted the fact that the family's experience had made them stronger as a family in the end.

AL: And was there any thing that was positive about looking after somebody with a mental illness?
Clover: I think it makes you closer at the same time, it's like you lose parts of the relationship but you gain in other ways. Like I think she trusts me, I know a lot of mothers who don't trust their kids at all, especially teenage girls, they just, there's no trust there at all but my mum trusts me 100%, I know she does. So yeah, it's strong in those kind of aspects and things, so that's one good thing.

The second positive aspect related to the ability of young carers to deal with people with whom others might feel uncomfortable, especially people with mental illnesses: Enid described it as being comfortable dealing with 'odd' people. She highlighted the understanding and insight into mental illness that young people who care for parents with mental illnesses develop, and another participant added to this by illustrating how she was better equipped by her experience to help people with mental illnesses.

AL: Has there been good things as well about looking after somebody with a mental illness?
Enid: I think probably it's populating the world with psychologists. So every one I meet with a parent with a mental illness is a psychologist. So I think it means that there are people who have a very good understanding of mental illness and a lot of insight about it in the world to be able to talk about it in that way, different to how a spouse or a sibling would, I think that relationship with your parent being ill is very different and it means that you probably have a lot more kind of compassion about it and maybe, especially in my situation where it's been my whole life, very kind of intrinsic understanding of what's going on and comfortableness with it.

Pauline summarised this by stating that she would not change her life, in spite of her caregiving experience and its impact.

AL: Was there anything you liked about caring or anything that made you feel good?
Pauline: I wouldn't change our life. Obviously it would have been nice if C**** hadn't have died, obviously, but I wouldn't have it any other way, I wouldn't want someone to have come in and taken my mum away or had carers come in.

All in the family

This main theme incorporates all the themes relating to the family and relationships within the family: these included the impact of the illness and caregiving on the family and on the other siblings, the role of parents in caregiving, and the issue of blame within the family. It also included the nature of the relationship the young carer shared with an ill parent and whether that relationship was reciprocal or not. Finally two semantic (interpretative) themes - the protective circle formed by the existence of family support and the issue of being a sole carer (a young carer who is the only person available to look after the person with the illness) - and the relationship between these two themes are described.

Impact on family

The supporting text for this theme mainly came from families where a sibling was the person needing care and there were parents involved in providing care. Caregiving could be difficult, upsetting and stressful for the family as a whole, with one young carer describing it as a "joint production" from the whole family. The impact of the illness could be seen in the distress caused, in the difficulties faced by a family trying to

plan family outings, or in parents who had to give up work to care for a child. In three families the impact on the parents' health could be seen when a parent developed a mental illness as a result of caring for a child/spouse with an illness, even if they had difficulty in recognising the impact of the illness on themselves.

> "Yeah, 'cause obviously she doesn't want to, I think she felt bad, like she felt like it was her responsibility to look after him and it took me like 3 or 4 years to persuade her that it's not good for him and it's not good for her. And literally T**** moved out and she was fine. It was so funny 'cause I kept saying to her that the reason why she's ill is because she's stressed out about T****, and she was like "Oh no no, that's not it, there's just something wrong". She quite likes to explain that she was ill because she had a chemical imbalance, that's what she liked to say, "No no, just a chemical imbalance, don't worry I'll take my pills and I'll be fine". As soon as he moved out she was fine and I was just like *sigh* but still then she didn't accept that that was what was making her ill, but whatever." Beatrice

The difference in the response to the illness between generations was also noted, with one young carer's description of her grandparents' difficulty in dealing with her mother's illness. For the older generation, it was more upsetting, and they found it hard to understand or to do anything about it.

While one young carer's parents found it difficult to accept the fact that their son had a mental illness, another's mother accepted it and "went into autopilot". The latter young carer felt that her mother's calm acceptance of her sister's illness was what kept the family together. The difference between the two reactions could be due to the family oriented (African) culture of the latter family which, according to the young carer, was what might have helped her mother be so accepting of the changes in her child. However, the former family also came from an ethnic minority community (Asian), where family ties are known to be important.

> "Maybe for my mum because where she grew up, just the country, it's very family orientated so it just helped her, that experience helped her to just take the changes in her child and just continue 'cause you can't change your family, so either you accept it or you are just going to drive yourself into insanity, so she just kind of took what was happening..." Naima

Finally, the impact of the illness on a family was also seen in the strain on marital relations when a spouse was ill. In one case, a young carer attributed her parents' divorce to the mental illness, in another, a young carer had to emotionally support both his parents when their relationship was struggling. In contrast, in a third family, the young carer felt that caring for her mother was the reason for her father's sustained recovery from depression, in spite of the fact that it must have been stressful for him.

> "And have my dad there as well 'cause I'm sure its affected him, it's just he doesn't really say much about it. I think that's one, that's one thing is that my dad has never been ill since he was ill, so it's almost as if that's his coping mechanism. I always wonder how he is doing about it 'cause it must be so hard for him to see my mum when she's down, and he's kind of lost his wife then. That's a lot of stress for him and yet he's been ill before, I mean what stops him from going back down that road. Is he doing it just to make sure my mum doesn't get worse?" Clover

Impact on other siblings

The impact of the illness on other siblings in the family was thought to depend on different factors, such as whether the other sibling was older or younger, and whether they were living at home when the major part of the illness occurred. Whether it was a sibling or a parent who was ill, if the other siblings had been away from home when the illness developed, they tended to be less aware and less affected by the illness. For the younger sibling (the young carer interviewed) who remained at home providing care, this could seem very unfair and was the reason for some anger.

"So yeah, he's never really experienced it which, I remember when I was at L****, probably in my second year looking back, I was so angry at him because I thought when I was 16 having to cope with this he was off at Uni in C**** doing physio and he was having a great time, and he was going out with his friends and he was ringing my dad up for money. And I was just *frustrated noise*, 'cause I had a job as well so I was having to cope with all of that on top of it. So yeah, I kind of hated him for that moment of my life. I realise he couldn't do anything about it, it wasn't his fault." Clover

Older siblings who were there when the illness became manifest were usually the first to shoulder the responsibility, even if they did not share the closest relationship with the ill person. The experience of caregiving could be very different for an older and a younger sibling.

"But as my sister got older, and I think she must have been 17 or 18, when she turned 18 and I was still 15, when I was at school, she became his next of kin, that's when she had to take on responsibility of dad and she had to go and see doctors and stuff, and all that stuff I kind of didn't want to be involved in anything, because I was so sick of dealing with dad, with him getting ill and constantly having to go through the kind of emotional roller coaster, and I kind of left her to deal with it, which, looking back on it now, obviously I behaved how I did, I was a teenager, I didn't really know how to behave, but I know my sister found that really hard because she'd never really had a close relationship with dad yet she had so much responsibility over his health." Antonia

Younger siblings who were at home during the illness were affected by it in different ways. One younger brother was described as the least affected of the family, yet even he found it stressful because he could not understand what was happening, and was concerned for his family. Another younger brother had to grow up quickly because of the experience of living with a parent with a mental illness. The focus on the ill sibling could lead to feelings of loneliness and attention-seeking behaviour in other siblings. The illness of a sibling could also bring well siblings closer, but this was indicated only in one instance.

"I was really angry about the whole situation, the same as my brother, he was, 'cause he was younger obviously, he's 20 now, there's 3 years between us and he started having a really bad time in school and just acting up, just didn't want to behave at all, just attention seeking, because the whole focus of my mum was on my sister and yeah, you kind of felt a bit lonely." Naima

Blame in the family

The emotional impact of the illness on the family could also be seen in the issue of blame directed by members of the family either at each other or themselves. One young carer, who was abused by her mother's boyfriend, believed that the incident was the

tipping point for her mother's depression. One young carer's parents blamed themselves for their child's mental illness. Other participants blamed the person who was ill for failing to control the illness or their behaviour. Two young carers were angry with their older siblings for leaving home and leaving their younger siblings to cope with the caregiving situation.

> "...'cause the problem with dad he takes, he's quite a heavy drug user and that was always what would start his episodes...
> ...But now it seems to be his own doing, because in the past he'd had episodes where he'd just stopped taking his medication and therefore he'd get ill, or he would start, he would take something, and now that's what it is.
> ...so from now I don't see him really getting 100% better unless he does something about it, because when dad's well you wouldn't tell he had an illness, when he's on medication he's like completely normal person." Antonia

Role of parents in caregiving

A minor theme in the group of family-related themes was the role of parents in caregiving. Participants described the kinds of support provided by parents for the ill sibling, which ranged from providing encouragement or a calming influence, to providing a home for the sibling, to constant 24 hour care. In spite of the role played by young carers in looking after their ill siblings, parents continued to play an important role too.

> AL: How..as in could you...How were you guys, you and your parents able to show him that you cared? And that he was really important to you?
> Mandy: So, I guess my parents' part was letting him live at home. Because a lot of, I mean he tried to go back to university again but then he had another breakdown and had to be sectioned again. But a lot of people, especially his friends, they get put into mental health housing. And for his friend, it didn't work, and he ended up dying of a drug overdose I think, and that was because he didn't..I'm pretty sure it was because he didn't have a home to go to. He had a home but it wasn't a constant...because you have to watch, I mean even now, he still drinks. And so what we do is we encourage him not to drink and if he comes back with alcohol, my parents will confiscate it.

The distribution of caregiving roles, particularly that of primary caregiver, between available parents and young carers is discussed in greater detail under the next theme 'who is the primary carer?'

Who is the primary carer in the family?

One of the questions that arose from the first few interviews was whom the family identified as the person with the main caring responsibility and whether this person differed from the primary carer identified by mental health services. Identifying the primary carer depends, in part, on who lives with the ill person. Irene identified herself as the main carer for her mother because she was the only person who lived with her. Rajini also lived alone with her mother who has depression.

> "Yeah, for a time I was, I am her carer so I'm her next of kin. I'm the only member of family that lives with her or near her, and has done for the whole time. So a lot of the onus is on me." Irene

Where there was more than one child living with a parent with a mental illness, it was usually the eldest child who took on the responsibility of the primary carer (e.g.

Pauline). When the eldest child moved away, the next sibling took on the caregiving responsibility (e.g. Enid). The exceptions were Antonia and her sister, who were named next of kin in turn to their father who had schizophrenia and thus had responsibility for his care, although they did not live with him. In their case, it was only when they became next of kin to their father that they really had to take on the responsibility for his care.

> "It wasn't so much, when I was a kid it wasn't really that much because I could kind of leave it, I could leave it because it didn't have to be my responsibility. I was a kid and I had adults, my grandparents were there, my aunt would go and see him, my mum would go and see him and if I didn't want anything to do with it I didn't have to, but now I don't have that. I am his next of kin, I'm the person, he doesn't have anyone..." Antonia

In most of these families with a parent with a mental illness, the young carer's parents were separated or divorced. However, Clover and Arthur lived with both their parents and shared the caregiving responsibility with the well parent. Clover described it as 'doing shifts' with her father, since he had to work, but Arthur was clear that his father was the primary carer for his mother.

> "So when I was living at home from 16-18 it was me and my dad both looking after her [Clover's mother] but it was obviously quite hard for my dad 'cause he had to work and I was at college so we were kind of doing shifts almost. And also at that time my brother had just left to go to university so he wasn't involved at all and to be honest, I don't even think he knows half of what happened and I've never really been able to tell him." Clover

The presence of a well parent, however, did not necessarily mean that he/she was most suited to be the primary carer, as seen in Enid's family.

> AL: So did watching how she [Enid's older sister] dealt with stuff make you decide to do particular things and not do particular things?
> Enid: Maybe, I think it was just more difficult for her because actually... so I was sort of 10 or 11 when my parents split up whereas she was 15, 16, and actually at that time my dad was around, other people should have been dealing with things and they weren't. And I think 'cause there was that confusion that actually nothing was being done but she shouldn't really the person that should be doing stuff, that was difficult, whereas by the time I got to that age it was just me, so I knew that it was me that was doing stuff and it wasn't, there wasn't anyone else around but that was OK, it wasn't like there were people there and they should be doing things.

Enid also supported the tendency for the primary carer to be living with the person with the illness in her description of the primary carer. It is important to reiterate, however, that caregiving does not necessarily cease when a person is no longer living with the person with the mental illness (e.g. Pauline).

> "And I think that's kind of an important role of somebody who's there all the time, and to be able to say "Well actually, that's not right" or "they're behaving in this way" or picking up on things which are, maybe other people aren't." Enid

Identifying the primary carer in a family was more difficult when it was a sibling who had a mental illness. In some cases, it was clear that a parent was the primary carer (e.g. Naima's mother), but siblings could also take on the role of primary carer, for example,

when both parents were working (e.g. Simon) or when parents had difficulty understanding English (e.g. Abdul's older sister and brother).

> "And right now she lives with my mum, she's always lived with my mum, my mum's a full time carer, me and my brother do what we can while trying to still live our lives kind of thing. Yeah that's the background with her." Naima

> "...and like I said, because my parents work full time and because I've been with him ever since he was young, I was always the primary carer, so I've taken care of him and what not and yeah that's about it." Simon

The allocation of the role of primary carer between a parent and a sibling was not always undisputed, and siblings could provide care in ways that parents could not. For example, Simon steadfastly declared himself to be his brother's primary carer, but his mother later took a year off from work, partly to look after Simon's brother and partly as the result of a breakdown. Despite having five older siblings, Beatrice was the only child at home with her parents when her brother returned home after hospitalization. She categorized her father and then herself as the primary carers, but described her father's caregiving as unhelpful. In Mandy's case, although her parents were the primary carers for her brother, Mandy's role was to prevent his drinking too much by accompanying him to the pub.

> "And so what we do is we and encourage him not to drink and if he comes back with alcohol, my parents will confiscate it. When he goes out to the pub, I will usually go with him, and that's one of the things that I would think would be really helpful. Because my parents they can't go, because they're too old. It's so important because whenever I don't go with him, he ends up staying out all night and getting very drunk. Not so much now, because he's on better medication." Mandy

The balance of caregiving responsibility could also shift with time, with a different family member taking on the primary role .

> "No my mum was registered carer for my sister but although me and my mum both cared for my sister, I would be honest mum probably did more at the beginning but then as the time went by, I probably had more involvement..." Tarun

Finally, regardless of the family's identification, the primary carer was not always recognised as such by mental health services, or even by the carers service, which could be confusing and make for difficult situations. In the following example with Irene, it was difficult to establish whether her aunt or the hospital was responsible for the situation that Irene had to face, but it serves as an example of the confusion that can exist with regard to identifying the primary carer in a family, or noting if there was more than one primary carer, both within the family and by services.

"I mean, when she came out of the hospital, last August? For a weekend? My aunt was bringing her home, she was – my mum was home for the night. My aunt stayed with her I believe. And I, I made it clear I was busy, I was doing a course, over the weekend. So I said, 'I'll see you on Saturday, but I won't be – I won't be able to stay very long da da da da' And then Sunday night came, and…mum called me. No, I got a voicemail from my aunt, to say, 'Oh, your mum did really well yesterday', and the voicemail was about at 5 o'clock Sunday (it was that long ago) it may have even been the Saturday? Yeah, so she was made to go home on the Sunday - so Sunday afternoon I get – the voicemail is left me, but I didn't listen to it until after 11 o'clock that evening. 'Oh your mum did really well so I spoke to the hospital, and I said you would be at home, so, they said mum can stay, your mum can stay at home tonight as well.' And I was like, what? Like, she's at home. I was saying to her, I was like, 'Mum, are you ok?' and she was like, 'Yeah, I think so.' And I was like, like, why hasn't anyone asked me if that's ok? I mean, I don't, I don't stay there, I never stay there, and I wasn't available at the weekend. And they just agree for her to be at home, like, completely without my consultation." Irene

To conclude, the identification of the family member who acts as the primary carer for the person with the mental illness cannot be assumed, especially by mental health services. It tends to depend on who is living with the ill person, on whether the ill person is a parent or a sibling, on the presence of a well parent, and on the sibling order, but none of these factors can be conclusively used to identify the primary carer. The primary role could also shift to a different family member over time. As one participant suggested, it might be helpful for mental health services to ask the ill person for a range of people with whom he/she shares a close relationship and to work with this group rather than an individual family carer.

"...you might have an immediate family member…in my case this isn't true, but you might have an immediate family member who happens to take the person to hospital but really doesn't look after them, or can't look after them because they're too old or something, and then you would have, I mean, because my brother's friend he does have a family but they're not looking after him, and so I guess maybe that would be a good idea if the patient was asked "Who do you spend your most time with?", "Who do you consider the person who's very close to you?" and give a range of people and maybe try and distribute the information to those people." Mandy

Relationship with the ill parent

This theme describes the relationship that participants shared with a parent who had a mental illness. In spite of the difficulties with their ill parent, each young carer identified positive elements in the relationship. For example, although Huy's mother was physically abusive to him during her illness and he wanted to escape from it, he also said they loved each other and his mother insisted on maintaining the parent role through the illness.

"It's not, it sounds really awful because on the other hand my mum is the nicest person in the world, d'you know what I mean. She is like Jekyll and Hyde. She can be so… I don't know, she can be caring, she can. She's just not, I think with her it's just her needs and her thoughts and fears always come first. D'you see what I mean, she can't put anyone, anyone before herself. " Pauline

Two other participants explained how they had to be careful not to upset their depressed mothers, and for one young carer, there was a lot of fear and distress associated with her mother being upset.

"And also I, whenever, if my mum's upset, I get really upset, I don't think it's a normal reaction, I don't know why I get that but if my mum is even a tiny bit upset or if I think that she's angry with me I just get really really upset, I can't deal with it at all until I know that she's not angry with me, so that makes it even worse." Rajini

Another participant believed that his mother was worried that her son blamed her for the impact of her mental illness on his education, and felt she needed to make up for lost time.

"And also my mum it's quite obvious my mum that she's like 'I wouldn't be able to forgive myself if I knew you didn't go to university because of me' so it was already like as she saw herself as getting better she started almost trying to over compensate and it still goes on now, trying to make up for lost time so for example, she will always try and arrange 'oh do you want to go to see a show in London together' sort of thing, always like as soon as we've seen one 'lets organise the next one' and if I say I need, like say if she says 'do you need anything for Christmas', if I mention one thing that's it, if I say yeah I could do with a pair of jeans she will end up over the course of the year buy me ten pairs of jeans, just trying to make up because she very much was worried that she thought I blamed her, the effect she had on my education because obviously her mental health issues." Arthur

Most of the young carers who were looking after an ill parent were caring for a mother, except for Antonia whose father had schizophrenia. The closeness of the mother-daughter relationship and the impact of its loss have been described earlier. Pauline was the exception, having shared a closer relationship with her father than with her ill mother.

Antonia's interview illustrated the special nature of the father-daughter relationship, and her anger at the change in him and their relationship when he was ill. Although her anger continued because their relationship was never the same again, she continued to be concerned for his well-being and to care for him.

"We used to go and stay weekends and we spent a lot of time with him and we got on really well, and I was always really interested in nature and going out on walks with my grand parents and my dad, and I had a real kind of similar interest in everything like nature, the environment, history, all sorts, me and my dad had, I really took after my dad in that sense..." Antonia

Young carers frequently shared a close relationship with their ill parents and, although there was a change in the relationship when the person was ill, the relationship usually continued to include positive aspects and reciprocal care and concern. This reciprocal nature of the caring relationship is further expanded in the next theme.

<u>Is the caring relationship between the young carer and the person cared for reciprocal?</u>

For most participants the caregiving relationship was reciprocal. The care provided by the ill person included emotional support, advice and practical housekeeping tasks. It was particularly interesting that two young carers consciously provided support by allowing their mothers to care for them.

> "And in some senses that's not looking after her, it's letting her look after me and get back into being normal and coming home and doing the dishes and making food and doing my washing and things like that, that actually that helps things being normal, whereas now where we're all far away, it's difficult for her to go back because it's nothing, sort of…" Enid

> "Oh it's a two way thing. I mean he looks after me emotionally, I guess... and then… yeah I guess I just always try and be there for him, you know... if he wants to do something" Mandy

Sometimes the young carer still benefited from the relationship even when the caregiving seemed to be only in one direction.

> AL: And has your relationship with your sister been two way or do you feel like it's been one way, you looking out for her?
> Naima: It's been, mainly it's me looking after her, but yeah, she gives me some feeling of completion 'cause she is my sister and I do feel protective of her. I care for her a lot and I want to be caring to her so. Just when she's happy it does make me feel happier, although the majority of the time I am the carer to her kind of thing. It doesn't really matter I don't mind how it is, it's just when she's stable it's rewarding in itself just to see that.

From the theme of loss we know that more than half the participants felt a change in the relationship with the ill person, but whether this meant that the caregiving relationship was no longer reciprocal was not as clear. For at least two of the young carers, when their mothers were very ill they were no longer able to look after their daughters as they had done previously.

> AL: What have you liked, disliked most about caring?
> Clover: Disliked most..probably losing the mother/daughter relationship that you're meant to have at that age. Yeah, it was kind of the tables had turned and I was looking after her and you shouldn't have to do that when you're 16. Yeah, I think we've managed to cope, develop that though, it's fine now. It's kind of back to normal in a way. Yeah, I just think at that age it's something that you shouldn't have to go through, and it's just unfair but you can't do anything about it.

For one participant the relationship seemed one way, in that she did everything for her mother, and Beatrice felt that her brother got more from their relationship than she did. Arthur felt that his mother had begun trying to make up for lost time as soon as she began to recover. She seemed to feel she had to compensate for the impact of her illness on her son.

Finally, Tarun felt guilty about benefiting from his relationship with his sister, because he believed that he had tried to control her.

"In terms of the world, I'd probably have a very odd idea and I'd have to then tell her and make it so she understands, so I'd say a lot of wrong things and I'd obviously, I don't know, you end up controlling people and I didn't like that about myself. I think as I got older I realised that, and now I've certainly realised the fact that how you're doing something for someone else's benefit and using it for your own benefit. I think it got to a point where I was, I was helping her but then I was also getting something out of it, you know like a co-dependent in a way. I don't know. And I feel guilty about it, I really do, that's how it affects me now." Tarun

Family Protective Circle (family support)

The family protective circle is the researcher's conception of the presence of family support as a circle of protection around the young carer, reducing the impact of the mental illness and caregiving. Participants recognised how much more difficult their experiences could have been without the support of family members in looking after the person who was ill. This support could be provided by a well parent or by other family carers and was evident in a parent's attempts to protect children from burden or in small gestures of affection. The responsibility of looking after the person with the mental illness was shared within the family, which made it easier. A family could emerge stronger from their experience (e.g. Clover's family).

"If it wasn't for his support I think I probably would have gone mad. But I've built up a network on our own, it's only having what you've got isn't it and without my brother and without L**** [her partner] and my dad it would be mad. They have been great. Some people, this is what I mean, there's people out there that deal with the same thing as my mum and don't have anybody..." Pauline

"It's the sort of thing where at the time when it first started happening I had no idea what was going on, as far as I was aware she was going to hospital again and the concept of being sectioned didn't mean a lot, and my dad made a conscious effort that I wouldn't go to the hospital while she was sectioned for example, especially at the start, he didn't want me seeing that, didn't want me being there to see that." Arthur

Sibling support also contributed to the family protective circle. Siblings protected each other and depended on each other for support, whether in caring for a parent or a sibling. A younger sibling could learn how to cope from an older sibling (e.g. Enid).

AL: Do you think it's affected your brother because you said that he tends to deal with it differently and...?
Pauline: Not half as much as it affected me. M**** [her younger brother] is strong, because he was sheltered from a lot of it as well because there's such a big age gap between us, it's like I didn't want him having to deal with all the stuff I dealt with, he doesn't deal with the bills, he didn't deal with chores or cooking and cleaning...

"Yeah, I can definitely, if not I learn about even more difficulties that are experienced by some of the young people, like one of the fortunate things about my situation is I have loads of siblings, so the responsibility of caring or looking after or looking out for somebody with a mental disorder is not solely on my shoulders but it's kind of distributed to everybody and everybody has to play a role, whereas some people that come to the young carers sessions, these are single children and they are really young, they have single parents as well, they're having to look after maybe their parent who has multiple sclerosis or something like that, so it's very shocking but it teaches me so much." Abdul

Mandy attributed her brother's recovery from mental illness to family support. She illustrated the protective nature of care by the family by comparing her brother's recovery with the tragic outcome without family support in his friend's case.

"Well there was never really anybody who really…he didn't really have anybody to look after him so his friend has now taken a lot more drugs and so he's having a bad time but I think he's taking the drugs because he doesn't have somebody to look after him. I mean my brother hasn't taken drugs since he was diagnosed in the first place, and that's because I won't let him near those people." Mandy

However, the same protectiveness of the family circle could also make confiding within the family more difficult. The ability to talk about their difficulties could be restricted by young carers' concerns about upsetting the ill person or their parents, or the parents' desire to protect their children from burden. One participant highlighted this issue because of the consequent difficulty she faced in obtaining information from her parents about her brother's illness. Parents wanted to protect their children but, as one young carer pointed out, the children were involved anyway.

There were instances, however, when family members were not always a source of support. For example, Antonia was closer to her father and felt that his illness had more of an impact on her than it did on her sister, so she could not derive any comfort from talking to her sister, nevertheless she felt her sister's absence after her sister moved away. Furthermore, as mentioned earlier, a young carer could be left feeling abandoned and unsupported when an older sibling moved away from home and seemed less affected by the mental illness. Antonia described how she was less likely to confide in her family as a teenager, and how she was able to talk more openly about her caregiving difficulties and experience as an adult with the rest of her family.

AL: Why do you think that was?
Antonia: I think, 'specially being a teenager, you don't immediately look for your family 'cause your friends are your first port of call, and I think as a teenage girl, your friends are your be all and end all, you tell them everything, and that was just the one subject I couldn't ever tell them. And even though my mum was always wanting me to talk about it, she'd sit me down, she tried to take me to a counsellor aged 14 and I was having none of it. It just really felt like I had no one to talk to, just no one.

The presence of other family members could reduce the impact of caregiving, particularly when contrasted with the experience of young carers coping alone.

<u>Sole caring</u>

Some participants were the sole caregivers for loved ones for a period of time, e.g. Irene and Rajini were each their mother's sole carer. Huy was the only person living with his

mother until he was put into his aunt's care. Enid became the sole carer for her mother after her sister went to University, as did Antonia when she became her father's next of kin. Having first cared for his sister, Tarun became his mother's sole carer after his sister took her own life.

The experience of those participants who were sole carers and lacked family support at some point in their caregiving could be contrasted with those within the family protective circle and the impact seemed greater with sole caring. Irene could contrast this time when she was her mother's sole carer with the previous time her mother was severely ill when Irene still had her family around her and she felt the impact was greater this time. Rajini's sense of isolation, intense relationship with her mother and her consequent distress at the thought of losing her mother to the illness was evident in the interview. Antonia felt that her responsibility as next of kin and her father's sole carer was more stressful than before. Tarun felt unable to live his own life because his mother would be left alone.

> AL: Did it, did you understand anything about going to hospital when you were small?
> Irene: No, I don't know... I think so… I must have done actually, but I don't remember it upsetting me regularly because I had, I still had a unit around me of like my brother and my dad, so it wasn't so... and where they've moved and my brother's moved, I had more of a relationship with my mum by this point so to have that broken down it was just, just awful.

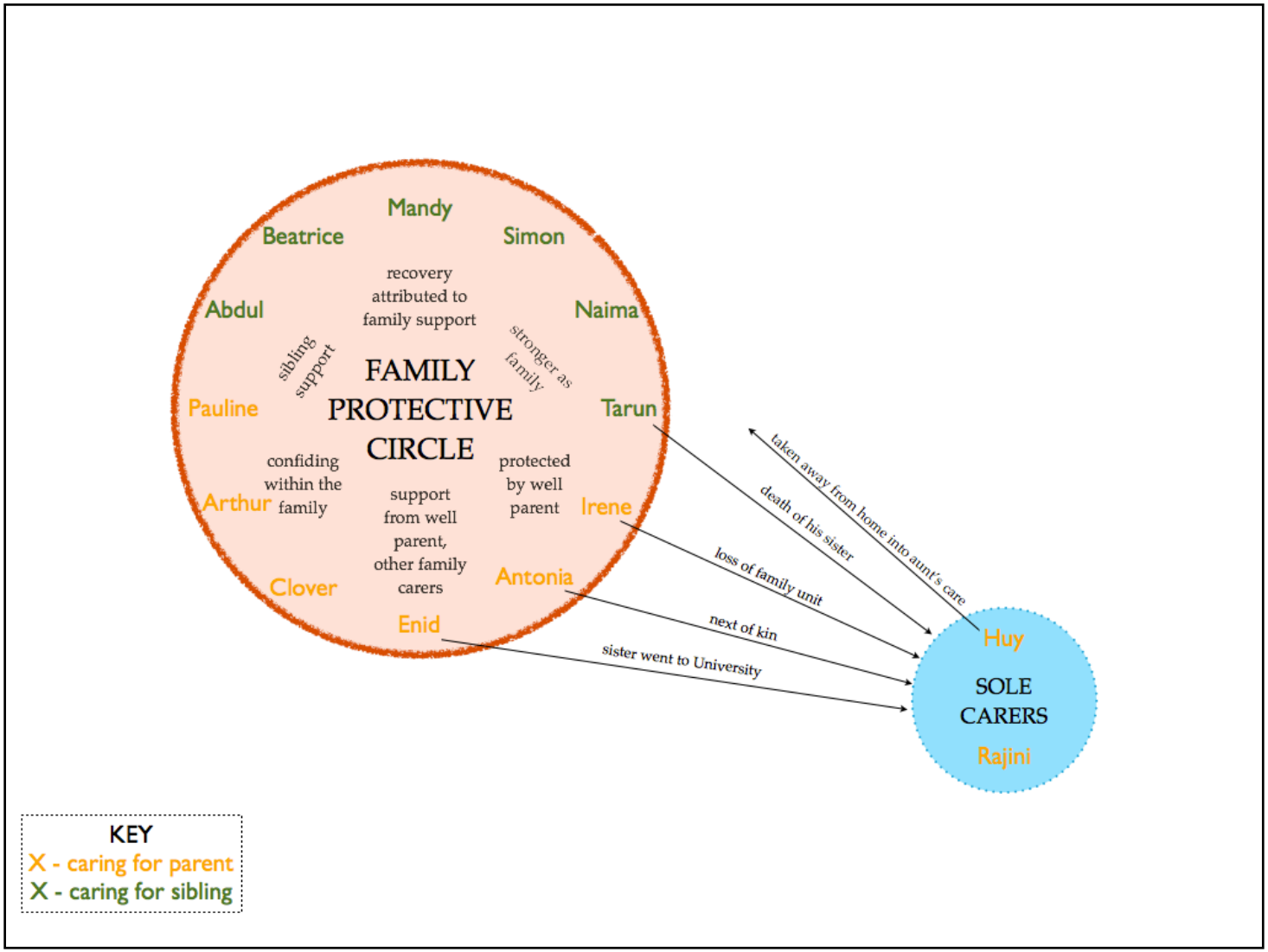
Sole carers did seem to be particularly vulnerable. Irene first illustrated this theme by describing her emotional vulnerability in her relationship with a boyfriend. Rajini's isolation and fear of losing her mother seemed indicative of vulnerability because she had no other protective resources.

While Enid found the caregiving experience difficult and upsetting, she was also less disturbed by the experience of being her mother's sole carer after her sister moved away. This was partly due to the support she had from her extended family and her school, partly due to learning from her sister, and partly due to her own positive coping strategy.

Even those who had family support felt that the experience was likely to be more difficult for those with sole caregiving responsibilities. Arthur, who was caring for both his parents and thus could be considered a sole carer, felt the support and protection of his father in looking after his mother and felt that a single parent situation would be more difficult. He also highlighted the likelihood of single parenting with mental illness given the association between relationship difficulties and mental illness. Even Antonia, who felt the stress of the responsibility as next of kin, could compare her own situation with her cousin's and appreciated the support she had from her mother and sister.

"And I think if I hadn't had my dad there it would have been so much more difficult, so for example if it had been a single parent. Like I know there was a girl that I heard about in one of the young carer projects like in the next town, she was looking after her mum who was a single parent who also had mental health issues so even though she was only 6 years old, she was staying up until three in the morning to make sure her mum went to sleep before she could go to bed, that sort of thing. If I was in that situation you don't know what to do because there's no one to turn to and I think especially because I can't say if this is statistically proven but in terms of where there's a mental health issue there is sometimes a lot of also where the relationship has broken down, so you have single, so looking at my young carers' group where a mental health issue was there there was a high rate of relationship break down so it was a single parent household mainly. And knowing what to do in that situation would have been much more difficult if my dad had not been there to help share the burden." Arthur

Participants believed that the experience of children and young people who were sole carers was particularly stressful and that this group needed additional support.


Mandy
Beatrice
Simon
recovery attributed to family support
Abdul
Naima
sibling support
FAMILY PROTECTIVE CIRCLE
stronger as family
Pauline
Tarun
confiding within the family
protected by well parent
Arthur
Irene
support from well parent, other family carers
Clover
Antonia
Enid
taken away from home into aunt's care
death of his sister
loss of family unit
next of kin
sister went to University
Huy
SOLE CARERS
Rajini
KEY
X - caring for parent
X - caring for sibling

Mapping participants with family support and sole carers

Figure 4.2 represents participants according to whether or not they had the support of immediate family members in their caregiving. Participants are also characterized by whether they cared for a parent or a sibling and any movement between the family protective circle and acting as sole carer is shown.

From this Figure it can be seen that all those caring for siblings were within the family protective circle, i.e. had family support, since they also had parents and siblings who were providing care. It is also important to note that participants' caregiving situations were not permanent. Participants could move from having family support to sole caring, as indicated by the arrows next to some participants in the Figure. This is an important point to consider given the protective influence of family support described above, since it means that young carers' family situations, and consequently their needs, could change.

Parents vs. siblings

There was some indication that caring for a parent might have more of an impact than caring for a sibling, especially considering the greater likelihood that those in the former category might be sole carers. Enid felt there was a difference between caring for a parent and a sibling because of the difference in the nature of the relationship with a parent, which exhibited itself in the greater understanding of mental illness shown by children of parents with mental illnesses.

Vulnerability was not only seen in sole carers' accounts: Pauline showed her vulnerability when she began to self-harm. Arthur, who was an only child caring for both parents although he recognised his father's support, also seemed vulnerable when he was bullied at school. This indicates that children of parents with mental illnesses might be more vulnerable than those who have siblings who are ill and need to be better supported.

The role of a young carer

The role of a young carer, or the ways by which a young carer provided care, ranged from an "as-and-when carer role" (Tarun) to constant attention to the needs of the ill person (Pauline). A young carer's role could also vary in intensity over the course of the illness. The responsibilities that comprised a young carer's role were mainly of three kinds: there were those that were more physical, those that were less tangible, and those that were more emotionally supportive.

The first category was concerned with physical tasks and material needs, and included helping the ill person physically, keeping house, translating and explaining information about an ill sibling's care for the benefit of the parents, visiting a loved one in hospital, providing respite for the primary carer and caring for other siblings in the family. It also included a monitoring role, for example, making sure the ill person was eating, drinking, and taking the proper medication, accompanying them to appointments, and keeping them occupied.

> "She wouldn't cook, or do anything. She wouldn't open her letters. She wouldn't do anything at all. I had to go and buy her food, buy her like, canned stuff so that it didn't go off and all that. Like make, her, like make arrangements with her, like 'I'm gonna come to dinner, this evening. You have to make dinner, you have to get up, have a shower…' like, she wouldn't wash, she wouldn't do anything, like a human does. She just wouldn't function. Through the whole, like almost the whole year, just gone." Irene

The second category involved less tangible support, including regularly checking up on the ill person, constant vigilance to prevent loved ones from hurting themselves or misusing alcohol and other substances, or dealing with emergency situations like overdoses.

> "...but like I said the main thing is he might get up in the morning and I would have to keep an eye on him at all times, make sure he doesn't go into some sort of trance you know have to be around him all the time, I couldn't leave him alone for 2 minutes. I had to keep an eye out to make sure he didn't hurt himself or someone else you know. We was lucky with that he never hurt anyone else you know, but that doesn't mean that he wouldn't have done, we couldn't guarantee that. He didn't know what he was doing." Simon

Some young carers felt they were having to cope with responsibilities that should have belonged to an adult. This included responsibilities belonging to both categories and tended to occur when parents could not deal with things they would normally be expected to do or when they depended on a young carer for advice. This could be stressful and annoying for the young carer. Beatrice described it as being treated like "the eldest male" while Clover felt like she was the mother in their situation.

> AL: And how was it for you to have to start dealing with stuff like that?
> Pauline: Extremely stressful, yeah really stressful because I mean, I was 16 and found she hadn't paid these bills for months and I was getting calls from like bailiffs and debt collectors saying she hadn't been paying this, she hadn't been paying that, and she won't deal with it all and you expect your parents to deal with these things, you don't have an adult that you can turn to so what the hell do I do, so you just have to get on with it.

Key to caring for somebody with a mental illness, however, was the emotional support. Arthur, whose parents had physical illnesses in addition to his mother's depression, could compare the two and could highlight the emotional care that was needed. This included acting as companion and confidante, keeping the person calm and avoiding upsetting them, keeping the person occupied, and keeping things normal at home to allow a parent to reintegrate herself into life after hospitalization. Significantly, the evidence of a young carer's support could be seen by the consequent effect on the parent when it was absent.

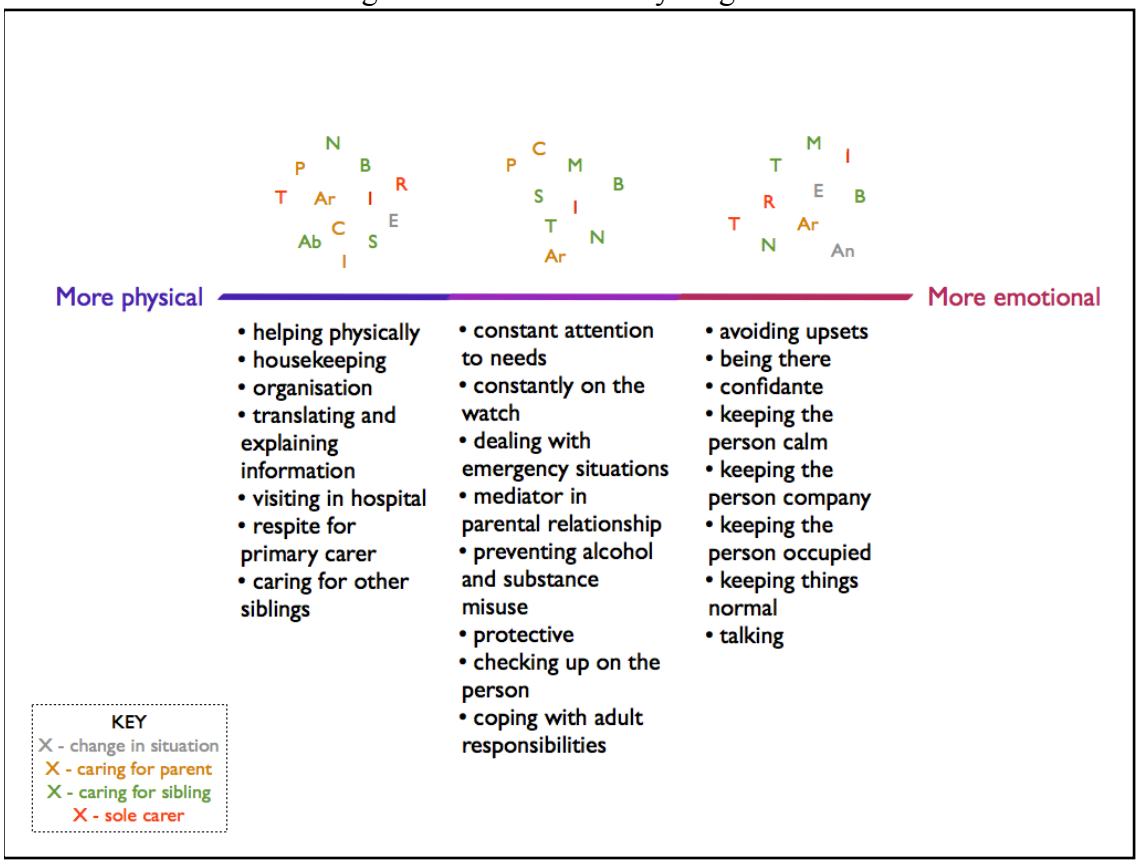
> "It's more sort of emotional support because I'm the only person that's there for her, so... I don't even know what I do really, it's more sort of if I'm not at home and I come home at the end of the day, my mum she just looks really bad and she just tells me that she's been feeling really bad and the house is a mess..." Rajini

Only one of the young carers described his caregiving role as limited or minimal and found it difficult to identify the ways in which he helped his mother. This was partly because he had been sent into the care of his aunt and was not allowed to see his mother very often. A discussion with another researcher who independently coded the transcript led to the consideration that this could be because the young carer viewed the definition of caregiving differently.

AL: Do you think you help to look after your mum?
Huy: Obviously now but back then I don't think because she was, no back then no. She was mainly looking after me but she didn't do a very good job. Now obviously yeah.
AL: Now like meaning since when? When do you think it sort of turned and you've started?
Huy: Probably last year or something, that's probably why I've joined the young carers project.
AL: Do you think that you need to look after her, not that you need to look after her but do you think that there are sort of caring jobs that you do for her?
Huy: I don't think I have a lot of job roles because some of the things she can do by herself but not a lot really. I used, sometimes I had to go over to see her nurse because, I don't know why, she's very lazy to go there, that's one of the things, and I can't really think. I don't think I have a lot of major roles in her life because she can manage on her own. That and I think very little minor roles to be honest.

The diagram below (Figure 4.3) illustrates the variety of care given by participants. There was no particular difference in the type of care giving tasks carried out by those caring for parents or siblings or sole carers.

Figure 4.3: The role of a young carer



The young carer - the expert

One of the key aspects to the young carers' role is their expertise on the people they look after. They were aware of the nature of the illness and its symptoms and could recognise when the person was unwell. They were familiar with the patient's full history and could describe what was going on to the psychiatric team and other services. They

had learned by experience what would help and how to deal with the person. This expertise was frequently compared to that of the health professionals.

> "Me and my mum knew that my sister was abused, we knew the history she'd had and we have all in our minds and I would expect a mental health professional to be sitting there with the same information in their hands, whereas it was all fragmented and everything was every where. Nobody knew my sister. We'd go into appointments and someone would ask a very daft question about "Why are you cutting yourself?" - they should have that before the meeting or before the appointment." Tarun

> "...because you can sense when she's getting more and more down, she becomes more withdrawn, she would be sleeping in all the day, would stop doing things, you could tell just by the tone of her voice that she was heading downwards in terms of her mental well being." Arthur

Their role as experts meant that young carers sometimes had to take the initiative to get information or to voice their concerns about the person for whom they cared, occasionally to the extent where they had to keep "going on at them". However, for one young carer taking the initiative meant that she was given the unwelcome responsibility of acting as the link between the hospital staff and other members of her family.

> "And I would also tell them to just pester psychiatric services until they do something, 'cause I don't think they do anything until it's at a point where, I think you have to communicate the problem that you're having and you don't get anywhere by being conservative about it and that's quite hard and I think if you can't sort of say it, then just keep calling and keep calling and keep calling, because that's the only way that they understand that it's bad enough for them to go." Enid

Conflicts arose when the young person's role as carer and expert on the person with the illness was not recognised by healthcare professionals, sometimes leaving the young carer feeling rejected. Although young carers wish mental health care staff to take account of their perspective, one participant recognised that this might not be appropriate when the the relationship between carer and person cared for is strained.

> "Not particularly, I mean obviously I haven't seen them as much. When it comes to that kind of thing its usually my younger brother, the brother who is ill and even my mum or my dad that go along and speak to them. I mean for some reason, even though I am the primary carer, they prefer to speak to a parent which I don't particularly think is a good idea but anyway, there's nothing I can do about that." Simon

This issue is discussed in further detail under the theme 'experience of mental health services' and as part of the suggested interventions.

Young carers' coping strategies

This theme describes the ways by which young carers dealt with the patient, the illness and the whole experience. It includes their experiences of seeking help from services, both for the person with the illness and for themselves. The categorisation of coping strategies has been developed inductively from the data rather than applying predetermined categories from current theories on coping. However, similarities to current classifications of coping strategies can nonetheless be seen.

A few of the young carers took up a strategy of avoidance to deal with their parent's illness, distancing themselves mentally from the situation or ignoring it and trying to

block it out. This state of affairs did not always continue and, for Clover, it meant that the emotional impact was felt much later.

> "And also because I am older, I just didn't like the reality of the situation so I just avoided going there for, you know, a long time really. But then I would start going every week and every few days." Irene

A few others found ways to escape, whether it was to remove themselves from the situation for a short time (e.g. work, studies) or to vent their emotions (e.g. writing, playing computer games). As Pauline described it, she just "had to get away". This method, however, did not work positively for all those who used it. For example, Irene tried to keep herself busy, to the extent where she began to get ill.

> "...but, mainly, just…well, I tried to occupy myself, that's how I coped through that time. But eventually I was so busy, all the time, I was getting run-down and ill from doing that. And I couldn't have a spare minute. I would start to get really anxious and panicky." Irene

> "It didn't affect it [her studies] at all really, because I just made sure, because I guess the only thing I had apart from my mum was studies, so in a way it was good for me to have something different to focus on, so I just focused on that and I didn't let go I guess." Rajini

Some of the young carers responded emotionally with anger or frustration at the person or the situation and Simon described the need to release his aggression.

> "I think it was because he wasn't there, like he wasn't my dad, he was this freak that I didn't know, and I was angry at that person and I wanted him to go and I wanted my real dad back, and I think I was angry because I couldn't do anything about it, it's not like a physical illness where if you take the medication then you know you'll see an improvement, like it took so long." Antonia

Young carers also used different cognitive methods of coping like accepting, questioning, and rationalising their situations, thinking positively, and deciding to change things.

> "'Cause my mum was abused she can't, even now my mum can't come near me, she won't give me a cuddle, my mum doesn't do female contact at all. She's not, she's always treated me and my brother completely differently, which now that I am an adult I accept, I don't really care any more but growing up it was always hard..." Pauline

Since caregiving could be a learning process, as mentioned earlier, some of the carers were able to cope by adapting to it. They had learned what to do and, as Tarun put it, "it becomes a way of life after a while".

> "Yeah. I think I know I would deal with it again. If she got ill again, I would definitely find it better just cuz I know what it's like, and sort of how it goes." Irene

Finally, some participants used active coping strategies to deal with the situation. Five of the young carers described how they just got on with it and did what they needed to do. Clover, for example, focused on trying to find ways to help her parents, but found it harder to help herself. Beatrice was able to talk things over with her sisters.

"To be 100% honest, you go in to that mode where you just blot it all out and just deal with it." Tarun

"I don't know, just got on with it, kept calm and carried on" Beatrice

Enid actively sought help from mental health services, getting them to come and help when she could no longer cope with her mother. She also described not coping as an active strategy, since she was able to recognise when she could no longer cope and had to just allow things to happen. She also recognised that it might be harder for those caring for chronically ill patients to cope, because they had to deal with things every day, whereas her mother's illness was more episodic.

"I think even when things get too much, there aren't really any options other than to kind of just let it happen. And maybe now I have a kind of higher tolerance for what is too much, because I have been at that point and been like 'I'm not coping' and then just not coped and let things happen and it's been all right, it's not been nice, but it's been ok." Enid

Getting help

An important part of young carers' coping strategies is that of seeking help for the person with the illness or for the young carer themselves. This includes who sought help and how, the difficulties faced and the pathway to help for the young carer.

In some cases it was the young carer, in others it was a family member who contacted health services to ask for help. In one case the school was instrumental in putting the ill young person in touch with the appropriate service.

Some participants had been wary of seeking help for their family member. Rajini and Pauline were afraid of getting help because of their fear of being separated from their mothers. Huy went through conflicting emotions because while he was afraid of what might happen to his mother and was reluctant to seek help, he found he was also happy and relieved when she was admitted to hospital because he was able to escape from his situation and his mother was going to get the care she needed.

There could be difficulties even when the person had already had psychiatric treatment. Enid found it easier to get help for her mother when she was continuously ill compared to when she had been well for a period because it meant starting from scratch with services when she fell ill again. She had also found it easier when she was younger to get services to respond. She described the 'in between' stage of wellness where her mother was not severely ill but needed to access services quickly. This highlighted the need for early intervention rather than waiting until the person had become severely ill and emergency action was needed. Huy also emphasised the need for getting help sooner because of the potential impact on the young carer's mental health by delaying support.

"Because I think I can relate this to any other person who has a mental heath, dealing with a mental health parent, you should, immediately you should tell a psychiatrist that if you're experiencing mental health or a parent you should immediately tell them because if you continue living through this sort of condition with your parent then your mind will experience a lot of things that won't be very pleasant and it won't be very good for you mental and then later on you will have to deal with those mental issues which take a very long time to make them go away and be very independent and concentrate on other life stuff." Huy

Even when steps were being taken to access services, there could still be obstacles to getting help; for example, Tarun faced difficulties getting through to the crisis team to get help for his sister who was abusing solvents. Office hours and the tendency, according to Enid, for emergencies to occur out of hours was another difficulty. There could be language barriers, as in the case of Huy's mother whose difficulty with English meant that she could not express herself clearly to the psychiatrist. Enid described the need to find the right terms to explain what was happening to the psychiatric team.

"And maybe now it's better that I've kind of got over saying things like "she's being aggressive" and "she's being problematic" or being promiscuous, the kind of words that people understand in the psychiatric team and will respond to and that is what it is, but when you're talking about somebody who is in your family, you don't immediately go "Oh they're being aggressive" or interpret it as aggression, you're just like "They're being mad", like "that's what it is, why can't you come out and deal with that?" I think finding the words to be able to explain to somebody exactly what's going on is something that really helps and something that they respond to and understand what's going on." Enid

Finally, the difficulty in getting help could arise through the patient, either because the patient does not want the carer to be involved, or because the patient does not recognise their need for help.

"So it would be a question of me literally dragging her up there and persuading her to get treatment when she really didn't want it, but then she will put herself in danger so she did want, in terms of she did really want treatment but while she was harming herself of course she didn't want treatment because that's a given in mental health, when you're harming yourself you don't want treatment but when you're not in that frame of mind where you know what your condition is and then you want to help yourself, then you are complying with it and they should help you. But what they're looking at, they're only looking at the side of her when she is in that frame of mind when she wants to harm herself, so they said "Obviously she doesn't want treatment", they're only looking at that side." Tarun

Enid's observation shows how differing perspectives could be the source of much frustration, when family members are feeling that something needs to be done while staff do not feel that the need is urgent.

"And then if you call up the office then they don't do anything and I think... I think it's just different for other people because I think if mum was on her own she would spend a lot more time being ill to an extent which I wouldn't tolerate if I was there. I wonder if the nurses, the psychiatric team, have a kind of higher threshold for when you need to do something, than I do. But I don't know, it's difficult to say, I think they see so many different kinds of patients, it's difficult to kind of communicate what's going on." Enid

Pathway to help for young carers

Some participants had also received support, mostly through the young carers projects through which they had been recruited. Referral to young carers projects came from a variety of sources. Irene had access to a carers' service and counselling through her doctor who had contacted the Council. Rajini and Simon were put in touch with the young carers' project through school and through his Life Coach respectively. Pauline got support from the young carers' project through her mother's social worker. Naima's family was contacted by the young carers' project. Tarun had limited support from a young adult carers project through his mother's contact with a family carers service.

Huy and Arthur got help when they could no longer cope with their situations; Huy said that he recognised that he needed psychiatric help and asked the police for it when they came around, whereas Arthur felt that his school only got him support from young carers after his attendance had dropped and the lack of understanding from teachers had caused him to walk out of school.

The pathway to getting help for somebody who is ill needs to be considered when planning support for young carers of people with mental illnesses, since getting help for the person with the illness usually results in helping the young carer. Similarly only some young carers had support for themselves, and sometimes the support only happened when the need became desperate. The questions that then need to be asked are 'how can more young carers access support?' and 'how can this support reach them earlier?'. Young carers' experiences of health and social care services, and mental health services in particular, is the key to understanding and improving their access to support.

Experience of mental health services

This theme includes both negative and positive experiences, the need for mutual understanding between staff and carers and the problems faced in dealing with services. This theme mostly relates to secondary mental health services, although occasionally experiences with primary care or social services were also mentioned.

Negative experiences of mental health services

Some young carers did not feel adequately supported by mental health services in caring for the person with a mental illness, while others felt that there were aspects that could be improved. Problems included lack of information, disappointment in staff and services, the need for involving the patient's family in care, and the effect on young carers.

Mental health services could be confusing and complicated for young carers as they tried to navigate the system, particularly when it seemed to work differently each time. The services provided by community psychiatric nurses (CPNs), GPs, ward staff, etc. could be variable.

"Well not straight away, I think that's always the frustration is that every time she was ill it seemed to be a different kind of system, you didn't know who to contact, you didn't know how to get involve people, I mean where my mum is they have a crisis team which we call the 'no bloody use in a crisis' team. They are fine after she's been in hospital but we don't need you now, it's good that they go out every day and see her afterwards but you think 'you're called the crisis team' and you call up and they go "Well she's not one of our patients". "I know she's not one of your patients because she's been well but now she's not", who do I call and it's just very difficult." Enid

"I don't know whether we were just really unlucky, because if you get a good CPN, it is kind of a pot luck sometimes whether you get a good CPN or a crap CPN, but like his CPN was just like beyond crap, like I think she had him for like 5 years and he saw her once or something. And it was like, it was crazy." Beatrice

Tarun's difficulty with the system was the lack of continuity in the treatment his sister received. The frequent change in the staff meant that the carer was the constant in the equation, possessing and able to provide information about the patient, and Tarun emphasised the need for better information-sharing between the professionals. Finally, Tarun also described the change and the lack of help after his sister turned 16 and was no longer under the care of children's services. He felt that the hospital should have, at the very least, signposted other services, including carers services, that they could access for support after his sister turned 16.

AL: Was there – do you have, or did you have any questions that you feel were not answered?
Irene: Yeah. A lot of the time, I would remember feeling really, always disappointed with the, the ward staff. I mean there are times when you would get somebody who was helpful, and who, you know, made you feel like it would be okay. But, to be honest, I think the problem really is that there are so many members of staff that rotate, so there's no consistency with a person or…you know, when you're there, the person working might not be one of the people that my mum talks to, or, or who like, has a watch on my mum or...I just felt like I had to always explain the situation to them, a lot. There are a lot of people in that ward but, I don't know. Maybe there's just not enough staff.

Families sometimes faced a lack of direction when they, and on one occasion hospital staff, did not know what they were meant to be doing. Tarun, for example, found the lack of information on discharge difficult because it meant that he and his mother had no idea how to care for his sister when she was misusing solvents.
Irene felt that her mother's discharge from hospital should have been more gradual, with staff consulting the carer and allowing her enough time to prepare for it. Although her family seemed to have been involved in the discharge process to some extent, she did not feel that this been enough. On the other hand, she had thrice found her mother at home after she had taken an overdose, which was understandably distressing.
Another way in which support from mental health services was felt to be inadequate was a lack of information. The information which young carers felt would have been useful was of three main kinds: (i) information relating to the illness itself when the person became ill or began to receive care, (ii) keeping the carer informed about what was happening during treatment and (iii) information for the family when the person

was discharged from hospital on what to expect, how to care for the person and who to call for help. Although some participants felt they had to find the information themselves and manage as best as they could there are instances of good practice as detailed under their positive experiences.

> "When he was ill, it takes so long. He's been ill for a year now and he's still not well, and the recovery takes so long and I didn't know what was going on, like I didn't know about the illness, no one had have ever sat down and explained to me, no nurse, no doctor had ever been "OK this is what your dad has, this is what we do to get him better, this is what we're trying", none of that. I've only ever had that now that I'm his next of kin." Antonia

There was also a need for services to involve the family in the patient's care both in and out of hospital. Participants felt that this should include more than just the primary caregiver in the family. For example, Mandy wished that she had more involvement in and information on her brother's care. When he visited her when their parents were away and he was going through a psychotic episode, Mandy did not know how to deal with the situation other than to contact his support worker who was not accessible. Simon pointed out that services needed to focus on what would help the patient most; this included speaking to the person with the most knowledge, which he felt in his case was the young carer rather than the parents.

> "I would have liked services to be more pro-active in trying to involve the family and explain because I think if my mum and dad would have felt that they'd have had support then they wouldn't have had to rely on me." Beatrice

On the other hand, it was not always easy to understand staff when they did try to communicate information, so services would need to keep families informed at their level of understanding. Abdul felt that there was gaps where his family did not know what was happening with his brother's care, although they had group feedback sessions with staff every three months. This raises the question of how to reconcile what carers see as adequate or sufficient information and what is feasible for services to provide.

> "I don't know, maybe going to these meetings and getting the staff, maybe getting, no actually I don't think the staff is such a good idea because they're on a different plane, so when they communicate it's not so easy to understand where they're coming from." Abdul

Some participants' negative experiences centred on their perception that health professionals did not listen to them or address their concerns. This occurred with primary care, secondary mental health services and emergency services. When Clover's mother was taken to the Accident & Emergency unit (A&E) after she had taken an overdose, she was discharged without anybody explaining to Clover what was going on, or assuaging her fear of it happening again.

> "They don't listen to you, as far as they are concerned you're just a kid, you don't know what you are talking about. One doctor actually said to me have I been to medical school. It's like no, but spend a week living in my house and you will see what it's like but no absolutely useless the doctors were." Pauline

Participants felt that staff should be more involved in anticipating risks and preventing crisis situations, to be responsible for patient and carer safety, rather than increasing the distress already felt by the young carers. This was the case for Irene who, not having

been kept informed, came home one day to find her mother on her doorstep in the middle of a psychotic episode while her social worker was trying to find doctors to assess her under the Mental Health Act. Irene did not feel safe but did not feel that she could leave her mother either while she was obviously unwell.

> "So, like, it was all just like, the sort of thing that I would prefer, prefer the professionals not to allow to happen. So, it was three times in total that I found my mum after taking an overdose. And like, it just seems like, for someone to take an overdose, and to be in that state, like, the people who care for her, which is always the mental health community, you know, the team there, that, they should know that that's a potential thing that could happen. And not only that, but for the one person that is, that lives with that patient, or is around that patient, to, to time and time again be in that, be brought into that situation – like, that could damage my mental health, you know? It just seems really like a careless way of being." Irene

> "...because they just discharged her without telling her or anything and then they said 'well, there's nothing we can do for you any more', so there's no treatment that's going to work, they've basically said you may be like this forever. I saw the letter." Rajini

The sense of disappointment at having been let down by staff and services was evident in some participants' accounts. Both Tarun and Irene felt that the approach taken was based on formal procedures rather than concern about the people involved. Antonia was able to compare her experiences with different hospitals, and suggested that a lack of interest in some hospitals could be due to a fast patient turnover, since her positive experience was with a hospital that had longer-term patients.

> "And then after that it would have been nice to have had a CPN. He did have a CPN but she was just crap and she never used to talk to us. And no one ever used to talk to us at all, nobody, we were just completely in the dark about everything and my mum and dad had to try and look after this guy that had schizophrenia and they didn't have a clue about what to do and they had no one to help them and I think that was really bad, I feel quite let down actually by services in that way." Beatrice

Thus, some participants felt they were just left to get on with it and had to sort things out themselves. On the other hand, they also recognised that there was only so much that could be done and that, because each person's illness experience is different, the same system does not work for everyone. They recognised that how things could be changed was not an easy question.

> "So yeah, I'll be honest I'm not happy with the way things are done, but at the end of the day nothing that could happen. I mean my sister's passed away, they can't treat her or anything. So I'm not happy and I wish that it could have been done differently, I'm not saying things would have turned out differently had they done things differently, but it certainly would have made our role a lot easier having more support from them." Tarun

"Not really, I think the only thing I would say is obviously a lot of my frustration and difficulty is about dealing with psychiatric services again. But I do actually think they're really good in this country and I think there's a lot of improvement needed but I feel quite lucky, that here they are good, and I do think that whenever I've ever dealt with somebody they've been very compassionate and understanding even with my mum, the psychiatric team anyway. They just kind of work within the system that doesn't really seem set up to deal with my mum's problems." Enid

Positive experiences of mental health services

There were positive instances in each interview where the family or the young carer had received support from services, whether it was GPs referring patients to the appropriate service, "good" CPNs, or the provision of supportive services like counselling and carer services through the local authority.

Examples of good practice included: being able to check up on the ill family member and express concerns, flexibility about a child visiting her mother in hospital, help for the patient that was immediate or preventive, and showing sympathy and understanding. Naima had a particularly good experience with mental health services when her sister was in hospital. Staff solicited her expertise, involved and listened to her family and referred her to a group for children who had somebody in hospital. Involving the family, listening to them and informing them about treatment and progress, making regular contact with the young carer and suggesting how to cope with the illness, and explaining the illness, treatment and sectioning, were all examples of practice that the young carer found helpful and positive.

"It was slightly later on when I would meet, they decided I should meet my mum's social worker so he can explain to me more which I found really beneficial actually, to understand what it actually means to suffer from schizophrenia, why is she doing these sort of things which I found really useful because up until then it's just like why is she doing this, she says she hears voices but what are these voices and just getting your head around those voices inside her head telling her to do various things was just really difficult to understand..." Arthur

"And I think that was the first time, I came out and I cried with relief, I was just so happy to have someone actually pay attention to what I was saying and care and actually feel like I was helpful. And I was just like I don't know why it's taken so long for someone to see that me is the person who spends the most time with him, I know his behaviour and I know when he's not well, I just never understood why they didn't value that. And so yeah, B**** was the only place where I actually felt that they cared and they understood, they kind of , it wasn't just another patient with a family to have to deal with..." Antonia

Need for mutual understanding

Some participants could see the point of view of staff while describing their experiences with health services and Enid highlighted the need for mutual understanding between staff and carers. She felt that each group needed to try to understand where the other's actions stemmed from.

AL: Do you think they do, and did they pay attention to you?
Enid: I think certain staff do and I think, I understand more now from just being a bit more aware of other people at the hospital, you know the nurses that have been there for a long time and have been seeing my mum for 15 years or more, know what her home situation is like and know what I'm like and will take on board what I say to an extent that they can because I'm not, I don't have any legal things, there's no advocacy agreement there or anything, to a certain extent they can't listen to everything. But people that you don't know, I think they're just trying to suss you out and I know that there are family members who visit people in hospital and you see them and you just think "Oh you're not good for this person" and I guess that it's, the nurses have to figure out where you are on that and how much help you really are in telling them things about what's going on.

What was difficult

Young carers described specific problems they had encountered in relation to the treatment of the person and services accessed. Enid faced difficulties in dealing with things like household bills and getting help from mental health services for her mother without authorisation, but at the same time found it very difficult to get her mother to sign a consent form giving her authority.

Confidentiality was a similarly difficult issue for young carers. This could be particularly hard to understand when the approach to patient confidentiality seemed inconsistent. The issue of information-sharing between professionals and carers has been studied (Pinfold et al., 2005) but participants suggested ways by which professionals could support young carers without breaking confidentiality. For example, the professionals could ask the patient how he/she would like the family to be involved, or they could provide young carers with information on how to support somebody with a mental illness. Mandy and Simon felt that their ill family members were likely to provide details of those family members with whom they shared a close relationship, so that professionals could include those people in care. Professionals still needed to recognise the level of expertise young carers possessed on the people they were looking after.

"But in 2007 which is when I literally pushed her to go to **** because she was going to do something, something bad was going to happen, I knew it, she, although I was involved in actually getting her started up there, they then said they can't discuss anything with me and it became that whole loop again and we ended up at step one again and I had to get in touch with them again, and although I pushed her towards that service, I really didn't know what happened after that. I didn't know what the outcome was, I didn't know what was discussed, which is fair and I understand that, the fact that it's my sister's privacy, she's entitled to that, but some indication of what to do would have helped, the fact that they could have called up and said "We can't tell you anything, but what we can do is tell you how to support somebody who has a mental health illness". They could have said something like that in terms of an anecdotal way but they didn't do that either." Tarun

The impact of young carers projects

This main theme focuses on young carers projects and services - what they offer to young carers, their impact and what can be improved.

Six participants had received support from young carers projects, one had received support from a carers service, one had received support both from a carers and a young

adult carers project and one had volunteered with a young carers project. Seven of them had been recruited through their carers/young carers project. Young carers projects provided a range of services which young carers found helpful. These included trips and activities, one-to-one sessions and counselling. Participants valued the opportunity to meet other young carers, to have an adult to talk to, to have somebody who seemed to care checking up on them, as well as having an outside focus and some time off from their caregiving. Staff at Arthur's young carers project had acted as an advocate for him, coming to his school to explain Arthur's situation to his teachers, to solicit support and to create awareness about young carers in the school.

"Yeah I really enjoyed it, it was the sort of thing where, especially between, so I benefitted most from it between 14 and 16 I think, having that sort of regular chance to have a break, meet other young carers who have experienced similar issues, also having someone there who could come in to school if things were bad, who could help trying to explain to teachers and make awareness, was something really beneficial." Arthur

Individual participants had found a different element of young carers services to be particularly suited to their needs and tastes. For example, Simon did not find counselling helpful but enjoyed the trips, whereas Pauline did not enjoy meeting other young carers and going out as a group so much. Having somebody to talk to seemed to be the feature of belonging to a young carers project that was most valued by most of the young carers.

"We don't do all the things with them. I don't feel the need to be around other young carers or things like that, I don't, do you know what I mean, I don't like pity and stuff like that. But H**** [project worker] I do get on really well with and we used to meet up every couple of weeks or whatever, every couple of months when things were stressful and it's just like an outlet, d'you know what I mean. They have been great and she's helped with a lot of things that I was dealing with my mum and that." Pauline

The positive emotional effect of the services could be seen in young carers' descriptions. Arthur described it as a place where he felt safe, with people who could understand what he was going through. The benefits of attending the project were clearly visible when his attendance at school improved. Naima found that the young carers project had helped with her anger by being an 'outside focus' in a life that revolved around her sister's illness. Both she and Pauline felt that it had acted as an outlet when things were stressful for them. Volunteering with a young carers project helped Abdul to develop a better understanding of mental illness and care giving. Participants who attended a project described at least one aspect as being helpful for them. The exception was Huy who said little about the young carers project and seemed to have been unable to take part in their activities because of his college work. However, the projects did not address all individual needs. Rajini's experience emphasises the particular need for isolated young carers to be identified and supported to avoid their isolation continuing within the project.

"I mean there was a group of boys who just all just stuck together, there were a group of girls who all stuck together and to be honest they seemed to be having, I mean aside from, I don't know what their caring responsibilities were, aside from that they seemed to be, from what they were talking about, the fact that they had gone out clubbing or that they had gone out with their boyfriend the night before so and so, they seemed to be having quite similar life to other people I have met at school who weren't young carers so it just seemed like ok, I've just come out of school and I've come into this and it seems exactly the same." Rajini

Abdul felt that a young carers project would be helpful even when there was more than one person in a family taking on the responsibility, as in his case. Although caring for somebody with a mental illness tended to be different from caring for somebody with a physical illness, Antonia still felt that meeting other young carers, not just those caring for people with mental illnesses, was likely to be helpful.

Although the number of young carers projects has been steadily growing, not all participants were aware of the services available and some were unsure about the criteria for accessing the support of a project. It was suggested that information about young carers projects could be disseminated through television and social media, with active engagement with families propounded as being more helpful than just information available. Earlier access was thought to be helpful. Rajini was over the worst of her experience when she was put in touch with a young carers project, but caregiving had had an impact on her social skills and left her very isolated, which meant that she could not benefit fully from the project. Moreover, there was no discussion about being a young carer between members of her group, many of whom were younger children, which meant that there was no one with whom she could share her experience. However, projects have limited resources and there is a need for creative thinking about other interventions to support young carers, rather than just adding to the responsibilities of young carers projects.

"I'm not saying get rid of young carers, like they're really good at what they do, but there's only so much they can do with limited resources and time." Arthur

One last question to be considered is the route through which young carers services are provided. While Beatrice felt that it would have been helpful to have somebody (an adult) to talk to, she felt she would not have used a young carers service unless it was at school, primarily because she would not have made the effort to go elsewhere. However, Huy also suggested the provision of young carers services through schools, because his mother would not have allowed him to attend the activities provided by the service very often, although she did not object to him attending activities at school. Providing services through schools might widen access to more young carers, including those hidden.

In conclusion, young carers projects provide valuable support in a variety of ways. While different aspects of the available services tend to appeal to each young carer, most still found the services very helpful. There are points to be considered with regard to expanding the impact of these services and these will be further detailed under the discussion of potential interventions.

Calling young carers

At the beginning of the project, when recruitment was very slow, the question arose as to whether young carers recognised themselves by the term 'young carer'. As reported in the Methods section, the wording of the advertisement poster and email were

amended by removing the term young carer and instead asking young people aged 16-25 who had someone in their family with a severe mental illness and who helped to look after them to contact the researcher if they were interested in taking part. Recruitment improved with this definition.

Does the term young carer work?

Most participants did recognise themselves to be carers and young carers, although some had come to realise this only later, for example, when they began to attend a young carers project (Simon) or even while discussing it during the research interview (Clover). As a young person and a carer, Simon felt the term was accurate, although initially he had not seen his role as caregiving until it was pointed out to him. Tarun recognised his caring role because his decisions for his own life were based on his mother's and his sister's needs.

> AL: What, do you think of yourself as a carer? And looking back, do you think you were a young carer?
> Irene: Yeah, looking back, I do. My mum never wanted to call me that – she didn't want to put that responsibility on me but, I...simply, like logistically, like, because I live here and no one else does, it was – I – of course I was her main carer 'cause, if anything happened I would be there before anyone else, you know? And it's easier for other family members to visit my mum but then go back to their home situation which I didn't do, so…you know. I mean, you know, buying her food when she wouldn't leave the house, and all that, really trying to make her eat something or…I mean, really trying to make her get up, like Christmas Day. And things like that.

Beatrice, in contrast, did not see herself as a young carer, because she felt that the term was for sole carers. This view was supported by some of the other participants who also felt that the term applied to young carers who had no else to help them. Mandy felt there needed to be a distinction between young carers with no support and young carers who had family support, particularly in terms of the interventions provided.

> "I don't know, I feel like a young carer is when there's no one else around at all to help, like a young carer like looking after the mum or something. Yeah because my mum and dad weren't particularly helpful but they were there. I don't think I would consider myself that." Beatrice

Enid, who was a sole carer for some time, felt that she was not a young carer since there were other young people who had much more to do when caring for an ill person, a view that was supported by Tarun and Naima. Moreover, both Tarun and Enid were uncertain about being classified as carers since the people they looked after had episodic illnesses which meant that the need for care giving was also episodic.

"I know there are young carers out there and when I see people who care for people who generally can't do anything themselves, my sister could do certain things as such, she went to college and she was quite able, she was very intelligent. If anything, she was much more intelligent than me. I think the difficulty I had is kind of find that distinction between when is she well, when isn't she well, when does she need my help. There were points when she was literally lying in her vomit and I had to call an ambulance, but there were other points when she was very able, and probably more able than me so I really don't know. It's a very ambiguous term carer to me, I really don't know how to define it, I think there were points when I was caring for my sister and there were also points when I wasn't doing so good by her. I really don't know." Tarun

Similarly, many of those participants who had recognised themselves to be young carers, still had distinctions to make. Naima pointed out that there were other young people who were caring full time whom she felt were the real young carers. Simon felt that there was not enough support for every young person and felt reluctant to take the place in a young project of somebody who might need it more.

The role of a young carer needs to be clarified when offering or advertising support for young carers. For example, in spite of having accessed some support from a young adult carers project, Tarun felt that support was available only for full-time or registered carers. Clover felt that young people just need to know where the support is, rather than being given a label.

"No, what I mean is that I don't think, I don't know what I'm trying to say, the people that are young carers, they're yeah, I guess I am yeah exactly the same as them definitely, or I am one of them, but I don't like the fact that you are kind of classified as a young carer because that suggests that it's a job while it's not a job, it's something that we're going through." Clover

Participants had further comments about the use of the term young carer. Pauline argued that the age of the carer did not make a difference, because there were pros and cons to caring at any age. Arthur suggested that the definition of a young carer could be expanded to include young people up to 24 years old, recognising the need for a different kind of support for older young carers. For Irene and Rajini the word carer implied looking after someone's physical needs. While the difference between caring for somebody with a physical illness and somebody with a mental illness has already been described, there was also felt to be a difference with respect to the term used. It was suggested that, instead of grouping all young carers under one definition, those caring for physical illnesses and those caring for mental illnesses needed to be identified separately, along with their unique needs. Mandy further stressed the need for mental illness to be viewed differently, as something that affects whole families.

AL: What do you see yourself as?
Rajini: Because it's, I mean, because caring to me seems like just talking about the physical aspects of it, just sort of you I don't know washing or doing the cleaning or cooking, making sure they have a shower, that sort of thing, but for me it sort of, it affects other aspects of my life and it's not just you go home and you do this and then that's it, that's just one part of your life. It's more like an emotional thing but I think that's not embodied in the fact that when you say I'm a young carer, I think carer has connotations of the physical aspect of it and not really the emotional aspect of it at all and especially in my situation, that's not really summed up by that term. But I don't really know how you would say anything else…

In spite of their responsibilities and mostly recognising themselves as young carers, participants associated the term with particular categories of young carers (full-time carers, sole carers). The term needs to be clarified when using it in advertisements or in offering support to young carers, so that young carers know whether their situations meet the definition and that they are eligible for support. However, none of the young carers had alternatives terms to suggest.

Sense of responsibility

The focus group first provided some insight into the defining characteristic of a carer, and this theme was identified in the interviews as well. Young carers felt a sense of responsibility, to a greater or lesser degree, towards the person they were looking after. In some of the interviews this was a semantic theme, e.g. Antonia who felt a responsibility to be supportive of her father and this increased greatly when she became his next of kin. In others, the sense of responsibility was more latent in the interview, e.g. Rajini who identified herself as her mother's source of support, describing herself as the "purpose of her life".

"...I mean, I see myself as a young carer because I have made very important decisions based on my mother's carers needs and my sister. There are a lot of things I wanted to do, I wanted to go travelling for a year, I wanted to move out to London but I couldn't do these things because they would have affected other people, and for that reason I think, because my decision doesn't just revolve around me, it affects other people." Tarun

The experience of a young carer: Findings from the focus group

Focus groups produce a different kind of data which allow the researcher to identify the shared meanings and common narrative; triangulating this data with that from the interviews can add to the understanding of the topic. The same thematic framework was used in the analysis of the focus group data.

While coding and analysing the data, it was noted that there seemed to be little disagreement between participants overall. Although it is difficult to know whether those who did not participate as much in the discussion agreed to what was being said, when they did participate, they seemed to concur with the others. The nature of the focus group discourse was helpful by the manner in which one participant would interrupt or continue from another's point, which made it an informative supplement to the interviews. The data from the focus group was also helpful in making conceptual connections between codes and themes.

It is to be noted that since one of the focus group participants, Simone, was seen to have a different caregiving experience from the other participants, any themes or codes that

came from her alone without support from other participants have not been included in the findings. This includes themes/codes from the exercises. It should also be noted that these were very few, since most of the points she made were supported by other participants. Participants have not been identified in the supporting text from the transcript because the large size of the focus group made it difficult to identify all the speakers in the audio recording.

Describing the experience

Similar to those interviewed, the participants in the focus group spoke of a shift to a new normality. They saw themselves going into carer mode and putting other people first.

> "It becomes a part of you as well, like when you from an early age when you're putting people first. I find that it manifests itself in different ways so if I'm with friends or anyone else I automatically go into that mode and it becomes a part of me, because as I was growing up, that was me, trying to help out with my sister. But now if I see anyone in trouble, I just forget myself and I think 'ok I have to help them, I have to help them', it's just become part of me in a way."

> "Normality really, that's our normality"

Caring could be a constant mental distraction and focus group participants also described it as trial and error, not being sure whether they were doing the right thing. Participants in the focus group also mentioned feelings of guilt and linked it to other people blaming them.

The participants recognised that the caring situation was probably frustrating for the person being looked after as well, and that they might feel resentful about needing to be looked after, and they sometimes found it difficult to get the right balance between looking after and restricting the person they were caring for. They could also see opportunities they had missed themselves, although it did not necessarily mean they wanted to change their situations. This could be exacerbated by friends who did not understand the situation and make it difficult for young carers to talk to other people about what they were going through.

> "I think my mum feels the guilt as well, with the same effect, I think she thinks that she's stopping my life, and that's not the case, it's just something that obviously I would do because of love, you do that kind of thing you know
>
> Have you ever like thought at any point like that resentment yourself like if I wasn't in this situation I could be doing this right now or I could be..
>
> Oh yeah, all the time, I get it from my mates. Some of them understand because I grew up with them so they kind of know that but I mean acquaintances wouldn't understand who don't really know you who don't understand the situation 'cause they don't know anything about it. So yeah, [occasionally?] I think about things I could have done, but yeah I wouldn't change it, it's just something you'd always do, any day."

The pathway to caring for focus group participants was related to other family carers moving away, as in the individual interviews. However, in the supporting narratives for this theme, young carers also seemed to have exercised more choice in taking on caregiving.

"When my parents divorced, even before that I thought of myself as a carer but I didn't really notice myself as a carer until I sort of hit that growing up stage, till I was about 10 or so, and then I thought well my parents aren't getting on, my parents were always apart from each other, they tried to stay apart as much as possible, and then when my parents did divorce, even though I went to live with my mum, I went back because my brother weren't really doing anything. He was just being that awkward 20 year old that don't care about doing anything. And when I went back, I felt a lot of stress and that, because I knew that I was a carer at that point, and when ***** Carers contacted me then that made me even more responsive that I am a carer, but I didn't really believe it for quite a while, because obviously, I was still getting cared for..."

Exercise I – describing the experience

One of the focusing exercises conducted in the focus group involved asking the young carers to say aloud words or phrases that came to mind when they thought about the caring experience to the researcher who wrote them down on a sheet of flipchart paper. A photograph of the sheet can be seen in Figure 4.4. This exercise was helpful in providing a snapshot of caregiving, as seen by young carers. Caregiving was seen as a responsibility. Some of the responses suggested that they felt that they had little choice over their future and they had to make sacrifices over their own lives. Caregiving could be a distraction. They mentioned feelings of depression, stress, confusion, desperation, paranoia and tiredness. There were also feelings of inadequacy, when they did not know what to do or felt like they were not doing enough. They found themselves questioning

Figure 4.4: Focus group exercise I

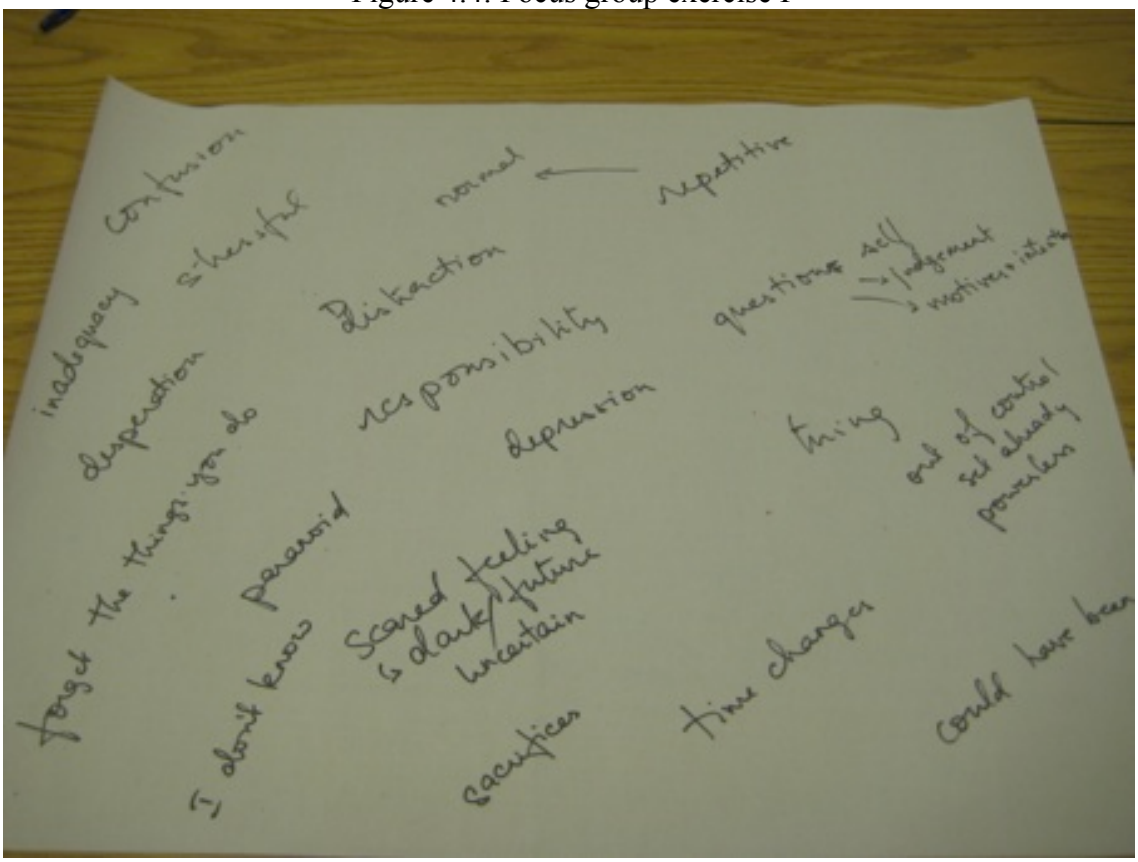


Figure 4.5: Focus group exercise II

their own judgements and motives. Time no longer felt constant, i.e. it was hard to estimate how long something had been happening, and because what they did tended to be repetitive, it felt normal and they forgot the things they did.

> Simone: When it becomes repetitive you forget the things you do. 'Cause you did cook dinner every day, 'cause you do do everything everyday, then you think 'what am I doing?'
>
> Time sort of changes as well. It feels like it's been a lot quicker because you've done it. You might have done a lot of things but because you've probably been doing a lot of the same things, it's not as long, or it may be the other way round...
>
> It's like you could just be sitting there for half a day or it feels like half the day but it's only been for half an hour.

Impact of caregiving

Caregiving had an impact on their education, since it could be distracting, and schools could add to the pressures. As with those interviewed, it was harder when teachers and peers did not understand their difficulties at home.

And after having to go to hospital everyday for a good week or so, that really put me on stretch for school, I had so much work to get on with, and then obviously I had to worry about him, and I never got my work done, which sort of severely changed my life 'cause I then had more problems catching up with everyone. I was always behind anyway 'cause I was a slow learner normally and kind of ever since I've left him, I've been quite a quick learner 'cause I haven't had to do everything for him, and like with work, I've learnt how to use the till and that quite quickly but when I was at school it just took me like ages to learn everything and it's just weird when...

School's quite a lot of pressure.

...Yeah, when you haven't got that pressure you can relax a bit...

Simone: Being a carer means you've got that constant mental distraction whatever you do with your hands

Participants felt that they had little control over their futures, that there were things they could have done but were prevented from doing by their caring situations. They also felt that their caregiving experience was not recognised as a skill when seeking employment.

They were also limited to some extent in their social activities. Restriction was made more difficult by a lack of understanding, which made young carers feel different from other people. The difference in levels of stressful situations, for example, was an area in which it was difficult for young carers to relate to other people.

Although participants felt a lack of choice, some felt that they would not change what they did, citing love as one of the reasons for caregiving.

Positive impact of caregiving

Similarly to the interviews, participants identified some positive results of caregiving: one participant was clear that the positive aspect of caregiving outweighed the negatives. Another participant (Simone) highlighted the valuable caregiving skills that she had developed from her experience. However, this was not always a positive impact, as another participant contrasted this with the fact that personal experience of caregiving was not considered to be suitable qualification for work as a carer by employers. Most of the support for this theme came from the second focus group exercise with post-it notes (what young carers liked about caring).

Exercise II – likes and dislikes

In a separate focusing exercise, participants were asked to write on separate post-it notes what they liked and disliked about being a young carer (Figure 4.5). These were collected and arranged by colour (i.e. likes and dislikes) and participants were invited to suggest ways in which they could be sorted or categorised. One suggestion was for the items to be sorted according to how it made them feel and how it impacted their lives. All but one of the examples used by young carers to clarify this fitted in with the researcher's understanding of this method of categorisation. For many of the responses (e.g. 'stressful', 'draining', 'depressing') it was difficult to establish to which category (feelings or impact) they belonged, since they were likely to be describing both feelings and the negative impact. Those that were more detailed seemed to mostly belong to feelings in general (e.g. 'Like I have to look after others as well and keep them safe as well').

What young carers disliked about caring – feelings

Participants in the focus group also described a gamut of negative feelings they attached to being a young carer: anger, depressing, draining, stressful, painful. Feeling responsible and feeling unwanted were both mentioned. They experienced feelings of guilt ('Like it's my fault it happened') and blame ('I feel like I dont[13] do enough'). Two participants wrote of being scared for different reasons, and another mentioned feeling like two different people. Stressful, guilt, blame and depressing were the most frequently noted feelings. It was suggested depression was linked to feeling drained.

What young carers disliked about caring – impact on life

The impact of caregiving on their own mental health was mentioned, and this seemed to be a particular concern for Simone. The restrictions imposed by their caring responsibilities, for example on social life or going out, and sacrifices made were also noted. There were several points made about the lack of understanding shown by other people and the stigma and discrimination sometimes faced. Two of the notes suggested an impact on the young carer's perspective, e.g. 'I'm cautious about things'. One participant wrote about 'seeing things you don't want to see' which did not seem to fit with any of the other categories. Finally, the researcher had categorised being scared for the future under feelings, but while discussing it with the focus group, it was suggested that it could be considered an impact, which seemed valid, given that fear for the future was also a result of caregiving responsibilities.

What young carers liked about caring

It was encouraging to note that there were positive aspects to being a young carer. The researcher identified the following themes or categories from the post-it notes:

(i) Bond with person cared for or family, e.g. 'get to spend time with family', 'develop a stronger bond with the person you care for'
(ii) Impact on the person cared for, e.g. 'making someones[14] life easier'
(iii) Support offered by young carer to family, e.g. 'get to help my mum look after my dad so I know she doesnt[15] have to go through it alone'
(iv) What it does for young carer, e.g. 'feel Respected', 'you get a feeling of accomplishment when helping them'
(v) Impact on young carer's outlook on life, e.g. 'it has enabled me 2B a more deeper person & 2 think deeply & making/managing every bit of time wisely'
(vi) Link with other people in a similar situation, e.g. 'feel able to help others who are in The Same Situation'

There were also three notes that did not fit into the above categories – 'can be easygoing being at home all the time' (this could have been Simone), 'You have reassurances that if the situation is under your control things won't go wrong. If the loved one is in care (professional care) you feel powerless' and 'making changes for people'.

Family support and sole caring

The theme of sole caring was raised in the focus group, with one participant feeling that caregiving would have been easier with sibling support, since her siblings were older and had moved away from home; this notion that caregiving is easier when shared was supported by another participant in the discussion.

The young carer - the expert

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[13] Spellings as given in the notes

[14] Spellings as given in the notes

[15] Spellings as given in the notes

The focus group also raised the issue of the expertise of the young carer. They discussed the need for their knowledge and their role to be recognised by staff and for staff to take into account what the young carer was saying, particularly when they were voicing their concerns about the ill person, for example, when the ill person was suicidal. Additionally, Simone highlighted the tension she faced between restricting her partner's freedom and keeping her safe, which was something that Tarun had also mentioned in his interview.

> Simone: I think as long as you're a recognised carer for a certain person, your words should have a lot more weight. It's like people go to the doctor's and they have their concerned parent sitting there worried about them, but unless the actual person says 'I've got a problem', it doesn't matter what their mum says. Even if they're 15, if their mum says I'm worried about this and their daughter's saying 'No, I'm fine mum, everything's fine', the doctor ain't gonna do anything. And you're thinking, this is like a child and a parent. And then you come to someone who is mentally disabled to the point that they're actually delusional or psychotic and they clearly cannot make the right decision for themselves, but being their carer and sitting with them 24/7 does not count for anything. It's like...I think that carers should be listened to by professionals more and taken seriously.

Negative experiences of mental health and other health services

The young carers in the focus group had also had negative experiences with health services. They particularly highlighted the feeling that health professionals had given up on their family members with long-term conditions, and described the emotional impact on themselves in terms of pressure, despondency and loneliness. They also mentioned losing faith in the system, as well as the feeling of being under scrutiny by professionals and wondering if their caregiving was adequate.

> They give up, don't they? They see that there's no point in helping any more 'cause they're not going to get any better and then they just leave it, just do what they gotta do.
>
> Yeah, and it sort of fades out a little bit
>
> *AL: Is this with mental illness or is it just physical?*
>
> Both
>
> Both
>
> Simone: Mental in mine
>
> Either way. They done it with my mother. They said that she would never get better, [we?] weren't helping anymore basically.
>
> *AL: How does that feel for you guys when things like that happen?*
>
> It's more pressure, more responsibility
>
> Pressure, yeah.
>
> More alone

The focus group - mainly Simone and Tarun - also raised the difficulty with patient confidentiality, when services would only deal with the person concerned. For them, it was particularly difficult when the person with the illness was unwilling to seek help and the carer could recognise that the person needed help, but services could not

provide help or information without the consent of the person. The young carers felt that professionals needed to listen to what they were saying and respect them as carers.

Calling young carers - do they see themselves as young carers?

While some of the young carers nodded in agreement to the question of whether they saw themselves as carers, two indicated that they only had limited caregiving roles, although it still affected their lives. Two others, including Simone, were reluctant to see themselves as carers sometimes because the people they looked after were unwilling to see them as their carers.

Sense of responsibility

Participants in the focus group highlighted the sense of responsibility as a defining characteristic of a carer. It could sometimes manifest itself as guilt when the young carer felt he/she was not doing enough or not doing the right thing. Their self-identification as carers and sense of responsibility that this entailed appeared to be determined by how much and how well they perceived themselves to be providing care.

> "...Feel like you don't know really, when you can't really cope and you're probably doing as much as you can, yeah. I think when things are bad, you know"

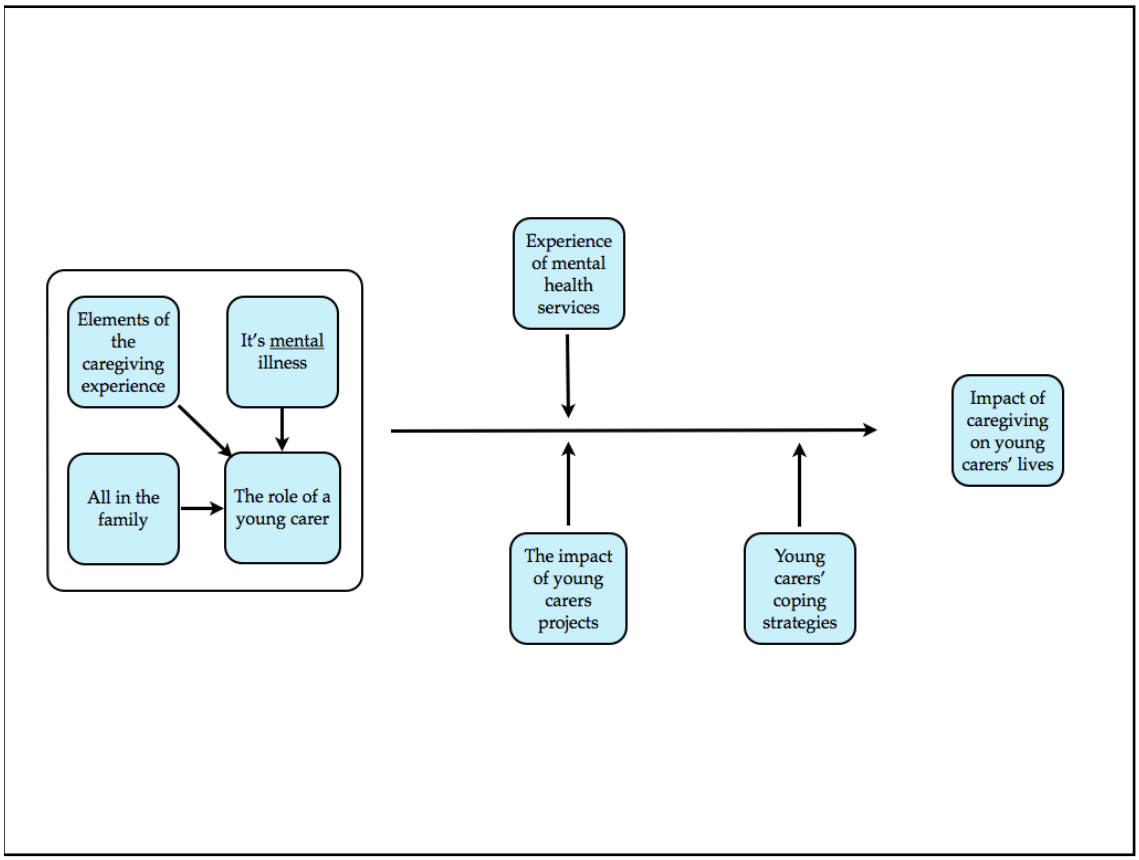
> "Umm...sometimes I see myself, I have my own mental health problems and when things deteriorate for me, I see myself as less of a carer because I think to myself, well 'you're not doing enough, you're not doing enough, you're not helping' but I know realistically, from a practical point of view, I do all the cooking, I do all the shopping, I do everything practical..." Simone

Results - theoretical frameworks

The experience of a young carer

The main themes that encapsulate the experience of a young carer were summarised in Figure 4.1. The relationships between themes is considered here and is represented diagrammatically in Figure 4.6. The role of a young carer, family-related themes ('all in the family'), the fact that the person being cared for has a mental illness ('it's mental illness') and the other elements of the caregiving experience contribute to the caregiving experience and its impact on the young carer. The difference between caring for mental illness and physical illness ('it's mental illness'), for example, affects the role of a young carer by the need for more emotional support and by the changing nature of the illness which causes the demands of the role to fluctuate. The loss of the relationship with a loved one ('all in the family') was part of the impact of the illness. The presence of family support ('family protective circle') or its absence ('sole caring') has been seen to influence the impact of caregiving on the young carer. The presence of another family member in the role of primary carer consequently affects the demands on the young carer. The level of choice ('elements of the caregiving experience') similarly affects the caregiving role, while cultural issues or being at the transitional stage can have an impact on the young carer.

Figure 4.6: Suggested relationships between the component themes of the experience of a young carer



As seen in Tarun and Irene's negative experiences of mental health services, the impact of dealing with emergency situations ('role of a young carer') might be reduced if staff acted to prevent crisis situations and to anticipate risks. Enid's coping strategy of getting help were felt by the researcher to be one of the moderators of the impact of being a sole carer on her experience, since she reduced the stress of her role by seeking help. The protective effect of young carers projects is demonstrated in the positive outcome for Arthur's education by the advocacy role of project staff.

The eight main themes provide analytical understanding of the experience of a young carer looking after someone with a mental illness. The effect of family support and the nature of mental illness on the role of a young carer, as well as the effect of the young carer's experience of mental health services, choice of coping strategy and support provided by a young carers project on the experience of a young carer, are important moderating factors to be considered in the support of a young carer of somebody with a mental illness.

Living with mental illness

The relationship between the following component themes of a young carer's experience - young carers' caregiving responsibilities ('the role of a young carer'), the presence or absence of family support ('family protective circle' and 'sole caring') and the impact of caregiving ('impact of caregiving on young carers' lives') - is of particular interest. The relationship between these three themes and whether or not a young carer was living with the ill family member was mapped for eight of the interviewed participants. This can be seen in Figure 4.7.

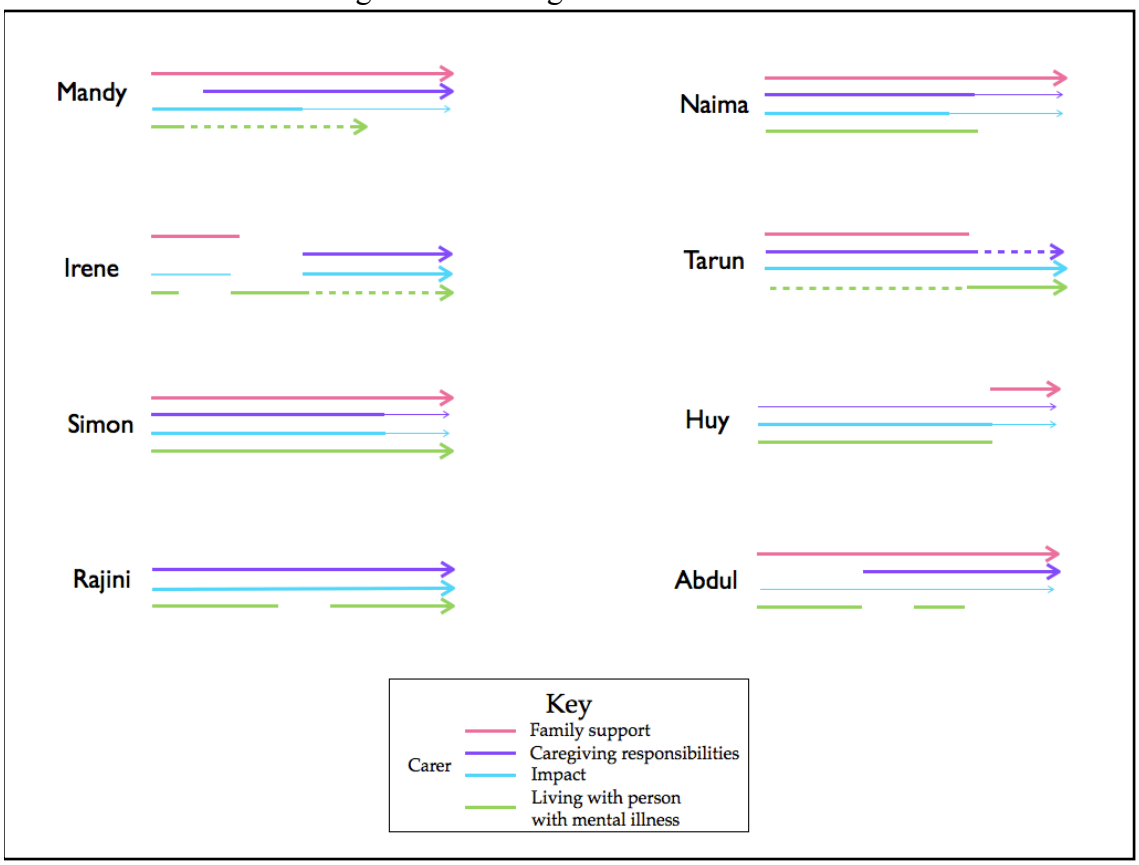
Each coloured arrow indicates the presence of the theme over time and a gap indicates its absence, in conjunction with the other themes. A dotted arrow indicates a periodic presence, e.g. when the young carer intermittently lived with the person who was ill. A narrower line shows a reduction in impact or responsibility, in comparison to an earlier

or later period in the young carer's narrative. The young carer's history of living with the mental illness is taken from their narrative, most of which is summarised in Table 4.3. While the lines show the themes over time, changes in situation over time, particularly those in relation to the other themes, are indicative rather than precise.

Eight of the interviewed participants' narratives were mapped in this figure to examine the relationships between the three themes and living with the person with the illness. Primarily, mapping these themes over time is important because it shows the presence or absence of one of the themes in conjunction with the others.

The figure shows that living with somebody with a mental illness, the impact from it and having a caregiving role are independent and not necessarily concurrent. A young carer can have caregiving responsibilities (e.g. Tarun) and be impacted by the experience (e.g. Irene), even when they are not living with the ill person. On the other hand, a young carer can also live with the ill person without being impacted by it, as was the case for Irene when her mother went through a period of recovery. Furthermore, living with the ill person could have an impact even when the young person did not have a caregiving role (e.g. Mandy, Huy). Comparing the impact between experiences, or even different types of impact, is to be avoided because it could belittle young carers' experiences without more research. However, Abdul is an example of a young carer who had a specific caregiving responsibility but seemed to have been minimally impacted by the experience, probably due to the number of other family carers around him.

Figure 4.7: Living with mental illness



The figure also shows that there can still be a need for support later, after the young carer's role has been reduced or when the young carer is no longer living with the person with the illness, because the impact can continue. For example, Tarun still bore a burden of guilt after his sister passed away.

This raises questions about the difference between a young carer and somebody living with a family member with a severe mental illness. While the experience can be more difficult with caregiving responsibilities, particularly as a sole carer, there can be an impact regardless of whether or not the young person has a caregiving role. Moreover, even those young carers with family support, who were not the primary carers, had been affected by the illness. If there can be an impact without a caregiving role, how are those children and young people being supported?

Need for support for young carers

To summarise: while the themes from this research have described the experience of young carers, they have also indicated the impact of caregiving, particularly unsupported caregiving. Where children and young people are left to deal with a single parent's mental illness by themselves, there can be a harmful impact. On the other hand, this can be reduced with support, e.g. from young carers groups. The impact of caregiving is not necessarily negative (see positive impact of caregiving under results from both interview and focus groups) but young carers need adequate support. Without pro-active work being done to support young carers, even more resources are likely to be needed later for those families or to help the young carers, for example, if their mental health decreases as a result.

Arthur stressed the importance of mental health, particularly with regard to supporting young carers looking after someone with a mental illness, given the lack of awareness about mental illness and the growing importance of mental illness as a public health issue. Without support, the impact on young carers and their mental health could be hidden.

AL: Were you able to get support from anybody? Before you met your partner there was the young carer service.

Pauline: Other than having H**** I didn't have. I mean I have a couple of, like my friend D**** that we've grown up together, she knows what my mum's like. I could phone her up and moan to her but I never had that kind of solid support, that's why me and my brother kinda tried to deal with it with ourselves. That's why I think I started self harming because I couldn't cope with that.

Mandy took part in the research because she felt it was important that both people with mental illnesses and their carers had access to support. She felt that when carers are supported in their caring, e.g. by keeping them informed about the care and treatment of the person they look after, they can in turn support the ill person and "a lot of terrible things could be prevented if everybody had that opportunity".

The provision of young carers services across the country can be variable. Some of the young carers felt it was the responsibility of the government to put more into supporting them. Moreover, the needs of young carers are likely to be different from those of adult carers, and this needs to be taken into consideration when planning support for carers.

"But I think because the needs are so different, lots of times yes this person may be having, you're caring for, may have the same needs but the effect it has on the carer which is often neglected can be so radically different. So if you've got an adult carer who is trying to balance a full time job and pay the bills, it's different to someone who is trying to cope at school with peers not understanding, teachers not understanding, the stresses of being a child weren't necessarily for them the finance, they don't see the issues there as much." Arthur

Finally, some of the young carers highlighted the importance of research on this topic.

"I think that when I saw the advert I was like I've got to go for this, because I do just feel like families are forgotten and that they shouldn't be. And I think that if families weren't forgotten then they'd probably reduce levels of depression quite a lot because I'm sure a lot of people who have like siblings or children or whatever with mental health problems are probably quite depressed and anxious." Beatrice

RESULTS: INTERVENTIONS FOR YOUNG CARERS

The second section of the results incorporates themes describing the ways by which the needs of young carers can be met. These themes relate to the second part of the research question, i.e. interventions that could potentially benefit young carers. This section compiles relevant data from both the interviews and the focus group. It should be noted that a more basic version of the analysis below was presented to the nominal group for discussion (see next chapter and Appendix), whereas the findings below are more detailed.

What could be helpful for young carers

Participants had many suggestions to make about what could be helpful for them and these were grouped into categories: information, dealing with the illness, contact for family in services, services, respite, somebody to talk to, meeting other people in a similar situation, young carers services, young adult carers and culturally specific.

Information

Young carers wanted different kinds of information: for example, regularly updated information about the different kinds of services available and how they can help in order for young carers to understand the mental healthcare system, and understanding what hospitalization can achieve. Information about the mental illness including its causes, what to expect, why the ill person might be feeling a particular way, what the young carer could do to help was also needed. Information tailored to the individual experience was needed to avoid contradictory and confusing advice.

"...but I think unless somebody's there to say this is how it relates to actually what you're experiencing, it doesn't mean anything for you to read the sort of symptoms of bipolar disorder..." Enid

Young carers also wanted to be kept informed about what was happening during the patient's care. It was proposed that services could facilitate information-sharing between members of the family, since parents sometimes felt reluctant to increase the burden on young carers. It was suggested that helping young carers to find the right terms to explain and describe a patient's behaviour could empower young carers in communicating with professionals. Providing information or actively engaging with

young carers could enable them to know what services and projects are available for them.

Dealing with the illness

Participants wanted to know what to do in particular situations or how to help the loved one who is ill. They needed guidance or reassurance that they were doing the 'right' thing. This could be facilitated by knowing who to call in a crisis or emergency situation. Not being given a number to call in emergencies and not knowing who to call, young carers felt could sometimes be dangerous. Suggestions were made for a number which young carers could call (potentially around the clock) to get advice and help from health or social services, but who should provide this service was less clear because, for example, it would be too much of a burden for young carers projects. An action plan or kit to be given to the family when a patient is discharged from hospital was also suggested, which could include the assessment of the illness by the mental health care team, what young carers could expect in terms of the illness, what they could do to support the person with the illness through recovery and what might make things worse. This meant that even if services were unable to support the family or the young carer, they were enabled to deal with the situation by themselves. It could also include guidance for young carers looking after people with episodic illnesses. While information about mental illnesses was available, there was little that was oriented towards those who had to deal with the illness.

> "It was frustrating at times because sometimes we found ourselves snatching aerosol cans from her in her room and it was getting quite mucky in terms of we really didn't know if we were doing the right thing and it was confusing, we didn't know what we were doing, we were put in a situation where we'd had no guidance, there was no instructions, there was nothing on the internet as to how to deal with such situations, so it's a lack of information and it was difficult at times and we didn't know really what we were doing." Tarun

> "Or just to have a phone number to ring coz I wasn't given anything like that, the GP never once spoke to me about, obviously coz of confidentiality so, yeah I mean I didn't know if anything went wrong, like when it did go wrong, I didn't know who to ring, I didn't know what to do and that was the scariest part because when she took the tablets I had absolutely no idea what to do. I remember thinking to myself, I was like 'Oh I'll call the ambulance, make sure that's on the way' and then I was trying to think of all my first aid that I'd learnt just in case she was unconscious or something like that, but I mean at the time it would have been really helpful to have just somebody on the end of the phone who deals with those kind of situations, that definitely would have helped." Clover

Contact for family in services

A further suggestion made in relation to support from services was for there to be a professional in the healthcare team who could support or "care for the carer", someone who could actively engage with the family. This person could provide information (see under *Information* theme) and suggest coping strategies to enable young carers to look after themselves while providing care. Young carers needed to be able to discuss their concerns with somebody. Group sessions for the family with the psychiatrist were

suggested by Clover as a way to support the family in realising what was happening and in coping with it.

> "I suppose on the more kind of, I don't know, like the administrative side, to try, for me it really helped having a name of someone I could ring up and say "Look I don't understand this" and this J*** woman was the woman who rang me and said "Look I'm the one responsible for sectioning your father, if you need to talk to me, if you need me to explain things, then give me a call" which was good." Antonia

Mental health services

In general, support from mental health services, particularly pro-active support, was helpful for young carers and examples of good practice have been described earlier (see positive experience of health services in previous section). Young carers highlighted a few ways in which services could support them, including recognition of their caring role and their first hand experience of the illness, and listening to them. Clover felt that it would be helpful for families to be supported in talking to each other about the illness and about their experience in a 'family support session'. Significantly, a suggestion was made for more integration of the NHS' (National Health Service) and family's roles in supporting the person who was ill.

> "Together, yeah, so it's not two distinct things, it's like both are working together to achieve the same objective, not the family fully relying solely on the NHS, not the NHS you know disintegrating from the family, and the patient who's in between understands that they're both doing it for me, not oh, how long am I going to be in here, and once I get out I'm going back home and I can get on with my life or get on with what I used to do. No, it's the fact that both the house and the NHS are working for your benefit, so that they can understand that whether you're at home or whether you're at the hospital, they're both doing their best for your interest." Abdul

Respite

Participants discussed the need for respite to enable them to step away from the caregiving situation and have some time to themselves. This could be provided by somebody coming in to look after the ill person. While going away was less of an option for Clover, because she would continue to worry about her mother, having somebody come in would have helped. Pauline was against carers coming in to support her, for financial reasons and because she found the concept scary and felt that professional carers would not know exactly how her mother liked things to be done. Another idea put forward was to help young carers to find new activities that would keep them motivated and help them to continue when they were finding things difficult. Focus group participants discussed the possibility of respite houses or holiday homes where both the young carer and the person cared for could take a break, with activities provided for families to come together, but also with the opportunity for the carers to do things by themselves, knowing that their loved ones were being looked after. Several participants in the focus group supported the suggestion that respite could provide the opportunity for the young carer and the ill person to spend time together in a more positive environment.

"I think one of the things I agree with you is the respite issue. I know that, probably got it wrong, I know when you've got respite, they take carers out, to help them get respite from the role, so here's a break, you don't have to care during this point, but then when you come back, you get to that environment again, that's your norm. But when you take the carer and the person you're caring for in a new environment, that gives you an opportunity to create a new norm, so you can say that it doesn't always have to be about the bad stuff, the mental health, you harming yourself, we can have a good experience in a different environment. " Focus group participant

Somebody to talk to

Young carers needed to be able to talk to someone who understood their experiences, whom they could contact for information, advice and support and for help with big decisions, who could help them get access to information. As Tarun suggested, this person might act as an advocate with services. Participants found it helpful to know that there was someone who cared about them, who kept in touch by phone or email and who would check up on them to make sure they were alright. Emotional support and seeing things from a new perspective were some of the benefits. Without this confidante, young carers could feel isolated.

Five participants had received formal counselling; some had found the opportunity to talk about their experiences helpful. Rajini had not found either art therapy or counselling to be helpful because of personal circumstances that had occurred at the time, while Antonia found it more appropriate when she was a little older.

This person needed to be an adult outside the family who could offer a neutral perspective on the situation. While having somebody in school to talk to could be helpful, Arthur cautioned against counselling being provided by a teacher, since it could prevent some people from accessing the service because of concerns about confidentiality. It could also be helpful if this person had some understanding of the cultural background of young carers from minority ethnic groups.

"Yeah, I mean you are scared of all this stuff and there's no one to talk to, there's no one to say yes, this is normal, no, it's not normal or, don't worry, they can't take you away, or just that bit of support just to say it's ok, have a moan, have a cry, whatever. There was nothing, honestly nothing and it was hard." Pauline

"...and also to have like, I don't know, just someone to talk to who maybe was older and didn't have any kind of relationship with the family or friendship with the family or anything like that, who kind of understood what was going on would have been good." Antonia

"I think the problem is because she's cultur... I mean she's English so she's culturally very different and some things upset me because of certain cultural things that have happened, sort of the way that my grandma and grandpa are, or how my mum is or so on and I can't talk to her about those things, because she generally thinks that any culture apart from English culture is absolutely perfect." Rajini

Meeting other people in a similar situation

Young carers projects already provide this type of opportunity and participants agreed that it helps to know that there are other people in a similar situation and that this can increase their understanding of their own situation and to feel supported. Some participants who had attended young carers projects had not found that they were able to talk about their experiences. It was recommended that projects could encourage young carers to share their experiences by providing activities during which they can open up to each other. This could be provided as support groups where young carers could meet other families or other young carers to discuss the changes in their lives due to mental illness and find out more. Such groups could help the young carer with their anger and to find better ways to cope with the situation. Mandy suggested that groups of people with illnesses and their carers could go out socially, since social support could have a positive effect, but other participants cautioned that it would depend on the circumstances and current health state of the ill person.

"And also no one was talking about the fact that they were a young carer, it was as if that didn't exist at all so yeah, I mean I would have liked to have been able to say 'Look, I don't speak to any one because I'm a young carer', I would have liked to speak to someone, just sort of shared my feelings with them or found someone similar to me but there didn't seem to be anyone at all…" Rajini

"Yeah they've [Young Carers Project] been good, it's a nice place to go and talk with the rest of the young carers, not so much now 'cause I don't really have time but when I was younger it helped because they do activity groups and days to the theatre or meals out, so it was just a chance to socialise but also vent your frustration with, and also it was a good opportunity to see that my situation is not the worst because some of the stories you hear are a million times worse than you are in, it put things into perspective." Naima

Young carers services

Young carers projects had been helpful in providing a break from caregiving and an opportunity to meet other young carers [see the impact of young carers projects]. Young carers particularly valued having somebody they could talk to about their experience. In one case, a young carers project had even provided a young carer with somebody who could come and explain his situation to his school. Naima's young carers project had indirectly helped her with her anger and helped her to cope better by providing an 'outside focus'. However, it was also recommended that young carers projects need to make sure young carers are regularly assessed in case their needs change.

Young adult carers

The transitional stage between 16-25 years was highlighted as a point when young carers continue to require support, albeit in different ways. They need to be supported in planning for their future, and enabled to feel that they can move on to do what they want to do. This could be provided by somebody who understands the issues involved. A service for young adult carers would need to be a tailored service, providing guidance and sign-posting to other relevant services, rather than providing respite.

"I think we've covered all of it, as I said one key thing I am really keen on is the transitional support because there are so many young carers out there who potentially would want to go on to university for example, or would want to move away but feel sort of tied down, coz like I said with me it's like, well how will my mum cope once I go away, and I think that is really important in terms of making sure there is that targeted provision to making sure that they can actually have, making the choices they want to make rather than settle for what they feel like they have to." Arthur

Culturally specific

Participants highlighted the need for more awareness and understanding of mental illness in both communities and individuals from minority ethnic groups. This could be facilitated by providing a culturally sensitive explanation of mental illness, with information on how to live with it and support recovery, by somebody who knows the culture in question and its perceptions of mental illness and who has experience of working with mental illness.

"How do you break the stigma attached to all of this mental health, especially coming from an Asian traditional family? Yeah, actually in Asian culture, if there's more awareness and more understanding of what a mental disorder or mental, schizophrenia, things like that is, maybe that can help my parents who come from these traditional backgrounds..." Abdul

Additional issues to be considered

In addition to the categories of interventions described above, there were more general points to be considered in the development of an intervention. Support for young carers and families, both within and outside mental health services, needs to be proactive, actively engaging with young carers and families and looking for ways to support them before crises arose. Even when young carers had received support, earlier recognition by doctors and teachers might have expedited the links to support.

Participants' accounts indicated a need for interventions to address early signs of stress and depression in young carers to help them remain psychologically healthy while providing care. The need for young carers to be aware of mental health problems and how to cope with these were identified as important, as is the ability to recognise one's own need for help. This requires greater public awareness of mental illness and being able to talk about mental illness openly, for example, was perceived to be helpful.

"I'd say intervention at the point where you're feeling stressed or depressed, because if I'm stressed out that's going to impact on my ability to be a carer and then I might end up doing more bad than good and I think certainly at that point, I think someone probably needs to talk to me." Focus group participant

Parents who are adequately supported in the care of an ill child or spouse, may be less dependent on other children in the family for support.

"...but I think knowing that somebody was there would have been helpful when they knew that they couldn't do anything any more and they'd ring me, so instead of ringing me they could ring this person." Beatrice

Participants found relationships and social activity groups outside the circle of the ill family member and caregiving helpful. Otherwise, as in Rajini's case, "I feel like it's just my mum, that's it, just my mum and that's my whole life, it's just my mum." Moreover, young people whose social skills have been affected by their carer role are

likely to benefit from additional support.. Young carers who are co-resident with the person for whom they care are more likely to be exposed to sources of stress. Some participants felt their ability to cope improved when they were no longer living with the parent with the illness; as Pauline put it, "I can deal with her now. I can deal with her because I know I can go home."

It was suggested that employers could be trained to understand how to accommodate carers' needs and that workshops in work places could be a way to raise awareness about carers in employment.

It was also felt that local authorities needed to be doing more to support young carers in a number of ways, rather than offering one oversubscribed young carers group. One participant stressed the importance of specific young carers strategies in which local health and social care and education services collaborate in identifying and supporting young carers. There would need to be checks in place to ensure that young carers and children were actually receiving the support to which they were entitled. Participants in the focus group suggested regular consultations with young carers before spending money on services. They also stressed the need for collaborative support for carers and patients instead of treating them as dissociated groups.

"...so for example how you're going to support young carers who are caring for someone who suffers from a mental illness in London where potentially your hospital is just down the road, you know mental hospital. It's very different if you've got someone who is living out in the middle of the country say in a rural area where there isn't a mental hospital for 20-30 miles..." Arthur

Advice for other young carers

On being asked what advice they would give other young people in similar situations, participants responded by suggesting ways of coping. This ranged from cognitive (e.g. being optimistic about the future) to more active ways of dealing with the situation (e.g. finding somebody to talk to). Emphasis was placed on actively seeking help from mental health services and from other people, both for the young carer as well as for the ill person, rather than trying to manage by oneself. Participants advised other young carers to make themselves heard and their needs known.

"If you're really shy, at first I was really shy, if the parent had you know or the child itself had mental health you should immediately tell the psychiatrist because its not good for you to keep your, if there's something you want to keep to yourself, if you have mental health or, then you're making things worse because the only person who knows that has a mental health you and the parent and no one else and nothing, no action is going to be done and then you are going to make things worse and it will be much sooner if you actually tell someone instead of just keeping it to yourself because you are missing out loads of stuff which you could get to if you sort something out now, that's what I say." Huy

What can schools do?

While it was helpful when their school was supportive, a lack of understanding from teachers could add to the pressure faced by young carers. In some cases, schools had played a role in getting help for participants or their siblings. However, Arthur felt that the situation nationally was a 'post code lottery' where some places had good support in place while other places did not. Whether individual young carers would want their teachers to be involved or want their peers to know about their lives at home needs to be

considered. Two participants seemed uncertain that support from school would have made a difference, but others felt that creating awareness about young carers in general in schools and universities would be helpful. Arthur found that with more awareness of his home situation, his teachers were better able to recognize signs of problems at home, and he was able to talk about his experience more openly. One example of good practice in another school quoted by a participant involved a discreet system which allowed a teacher to know that somebody was facing difficulties without the young carer having to divulge it in public. Schools could also provide support by being flexible about work and by providing somebody to whom young carers could talk. Two participants felt they would be likely to access help through school; for example, Huy suggested that organising activities for young carers through school and keeping parents informed about these activities could help young carers who are less likely to attend a young carers group. Finally, there could also be more education in schools about mental illness to raise awareness among pupils and teachers.

"...they should be made aware that young kids and children do have other responsibilities at home that can affect their performance and as a result it can affect their life." Tarun

"They were quite flexible with it but I think that that's a rarity, I think that was something that was good about that school was actually they understood the situation and were not gonna be like problematic about it, they were very sensible about things like end of year exams that didn't really count for anything, if they're not your GCSE's or your SATs it's just like just don't bother, it doesn't matter, we know how well you do, we're not going to take that into account." Enid

Supporting whole families

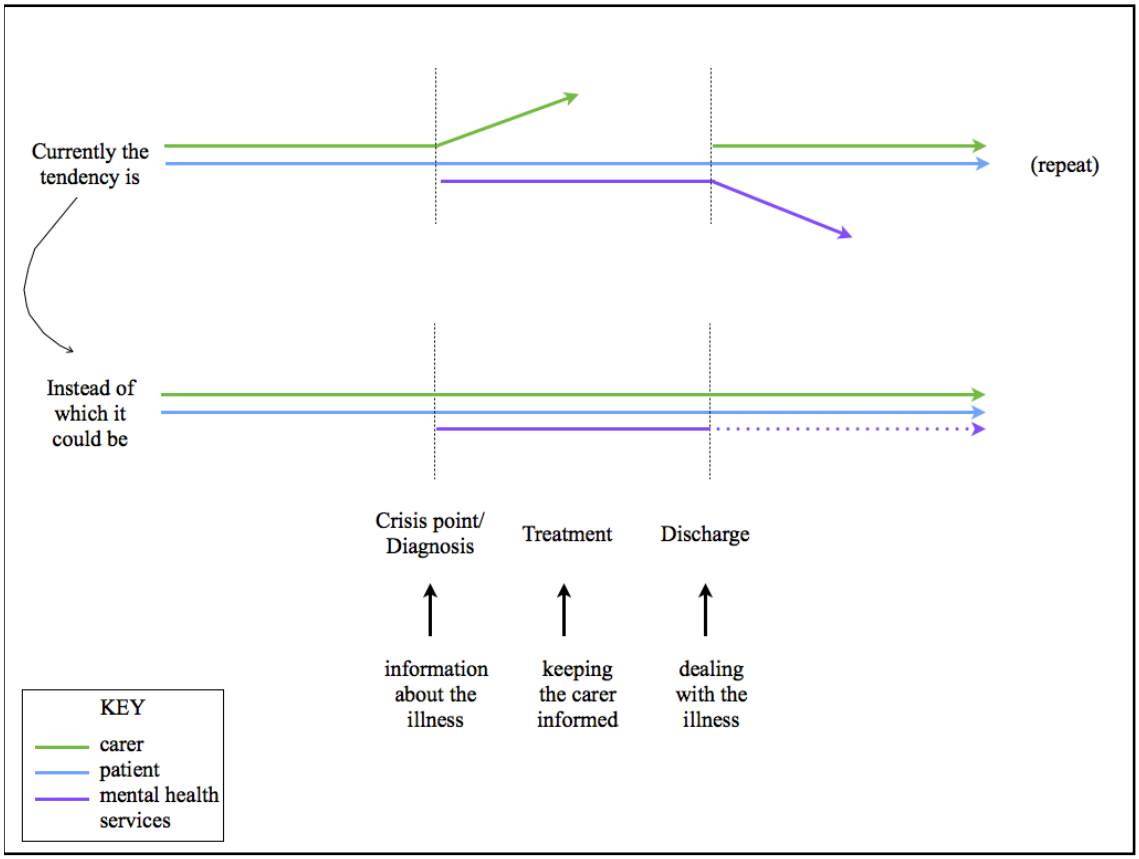
"I think in terms of a mental illness maybe people have to look at it differently and think that it's a thing that affects whole families." Mandy

Participants recognized the importance of considering the needs of families as a whole, to support them through the difficulties faced as a result of the illness. Mental health professionals need to remember that it is not only the closest relative who is affected, and that crises away from home still affect the people at home. Beatrice felt families tend to be forgotten and that supporting families could reduce the impact of caregiving on the mental health of children and siblings. It was suggested that this could be provided by something as simple as the psychiatrist enquiring after any children that a patient might have, or family support sessions to enable family members to talk to each other about the illness.

Another look at information

Participants emphasised the need for information, including information about the illness and services available, advice on how they might deal with the illness, and having a key contact in the mental health service who could explain what was going on and support the carer. There were a number of suggestions for providing this: mental health services, a new independent service, a young carers project. Figure 4.8 suggests a model by which young carers could be provided with the information they need, linked to the stages in the illness and treatment of the family member.

Figure 4.8: Providing young carers with the information they need at different stages of the illness



For some young carers, a loved one developed symptoms earlier (e.g. Mandy's brother), but it was only when the situation reached a crisis point that a mental health problem was diagnosed and treatment began. Usually at this point the young carer was no longer involved as the person underwent a period of treatment, either at home or in hospital (e.g. Clover, Tarun). With parents, the illness might be known, but there could still be points of crisis and treatment (e.g. Arthur, Antonia). If the person had been hospitalised, they might return to the care of their families on being discharged (e.g. Beatrice, Enid).

The model indicates the need for information at three different stages. When a loved one is diagnosed and treatment begins, young carers wanted tailored practical information about the illness, its causes, what could be expected, what hospitalisation can achieve, and to be able to discuss their concerns. During treatment, the young carer needs to be kept informed about what is happening to the patient. On discharge, the young carer needs to know how to deal with the illness: what to expect, who to call in an emergency, how to help the person. If treatment takes place while the person is at home, then stages 2 and 3 could be combined, providing young carers with the information they need to look after the person and keeping them informed about treatment. Recognition of young carers' role and experience, listening to them and the need for involvement of family are overarching principles in this model. Providing information in this way could facilitate a situation where staff and carers work together in support of the patient.

A tailored approach

Participants' accounts reveal very different experiences and roles depending on whether or not they had family support, the prognosis of the illness and a variety of other factors described earlier. Each young carer found a different type of support to be most valuable; while some desired information about the illness, others felt that information

was not helpful unless it was tailored to their individual experience. An intervention for young carers will probably need to use a tailored approach, to meet the different needs of young carers. For example, a young person who has family support might only need information whereas a sole carer is likely to need more intensive support.

> "I think certainly as you get older and you look for information to help you, I often find people pushing literature towards me, like leaflets and things like that, so they're implying that the consensus is on caring when there's not, I mean what I'm hearing from everybody, everyone's got a different sort of situation, there's not everyone who's got exactly the same role, but the way leaflets are, they'll give you one number to call. It would be good to have a tailored approach, if somebody there can actually listen to your problem and really listen to your issues and give you some custom-made solution, as opposed to a leaflet or a number, which is daft, that thing would be ideal." Tarun

> "I think it's the same sort of thing because it's so different for everyone, to put a system in place, some protocol that's the same for everyone is really difficult, and everybody just ends up finding things unsatisfactory and not tailored to them at all, so it's just a tricky subject to deal with." Enid

Summary

Participants put forward a number of different support needs and ways in which these could be met. These are examined further in the next chapter. They also highlighted the importance of supporting whole families and tailored support. A model for providing young carers with the information they need at different stages of the person's illness was suggested.

Appendix 2.8 Transition from initial themes to stress process model

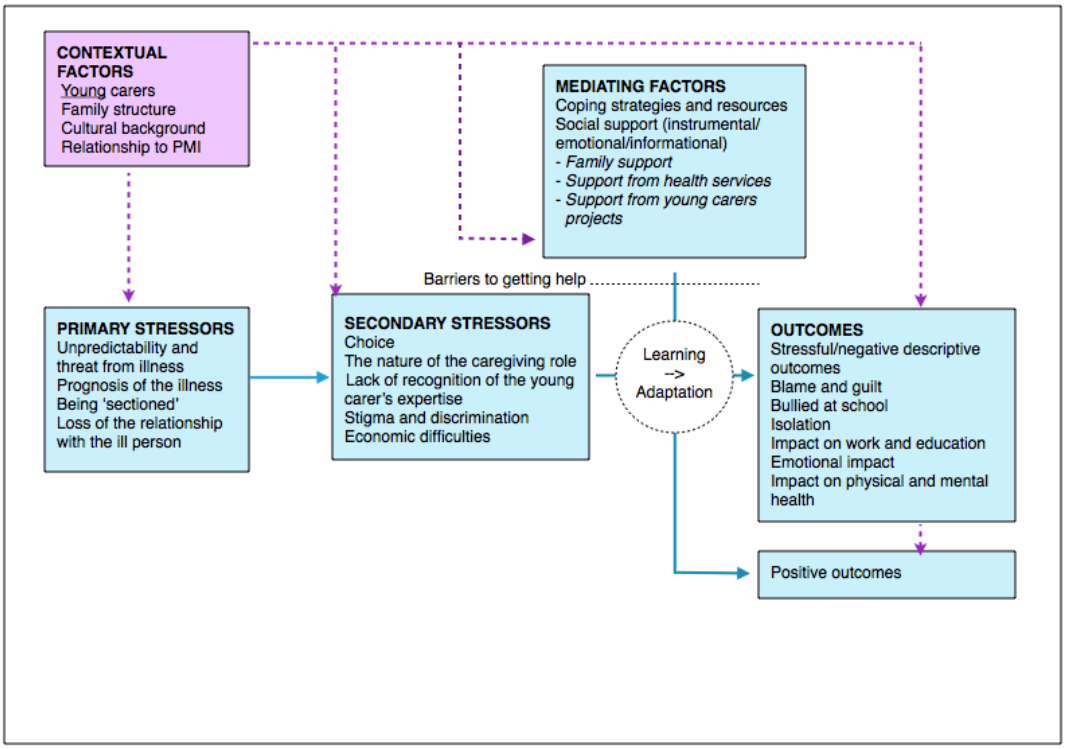
Initial inductive thematic analysis

The Experience of a Young Carer		**Interventions for Young Carers**	
Findings from the interviews	**Findings from the focus group**	**What could be helpful for young carers**	**Additional issues to be considered**
Elements of the caregiving experience • Young carers' descriptions of their experience • Young carers' concerns • Pathway to caring • Choice in taking on a caregiving role • What young carers found difficult about caregiving • Understanding the experience of caregiving at a young age • Understanding the transitional stage of a young carer's experience • Cultural issues	Describing the experience • Exercise I – describing the experience	Information	**Advice for other young carers**
It's a *mental* illness • Difference between caring for mental illness and physical illness • Being 'sectioned' • Crisis point • Recovery • Stigma and discrimination • Understanding mental illness • Discussing mental illness within the family	Impact of caregiving • Positive impact of caregiving	Dealing with the illness	**What can schools do?**
Impact of caregiving on young carers' lives • Impact on education and work • Impact on social lives, skills and relationships • Impact on young carer's mental health • Everyday impact • Problems with finances and benefits • Emotional impact of caregiving • Impact on physical health • Distress • Loss • Positive impact of caregiving	Exercise II - Likes and dislikes • What young carers disliked about caring – feelings • What young carers disliked about caring – impact on life • What young carers liked about caring	Contact for family in services	**Supporting whole families**

The Experience of a Young Carer		**Interventions for Young Carers**	
All in the family • Impact on family • Impact on other siblings • Blame in the family • Role of parents in caregiving • Who is the primary carer in the family? • Relationship with the ill parent • Is the caring relationship between the young carer and the person cared for reciprocal? • Family Protective Circle (family support) • Sole caring • Mapping participants with family support and sole carers • Parents vs. siblings	Family support and sole caring	Mental health services	**Another look at information**
The role of a young carer • The young carer - the expert	The young carer - the expert	Respite	**A tailored approach**
Young carer's coping strategies • Getting help • Pathway to help for young carers	Negative experiences of mental health and other health services	Somebody to talk to	
Experience of mental health services • Negative experiences of mental health services • Positive experiences of mental health services • Need for mutual understanding • What was difficult	Calling young carers - do they see themselves as young carers? • Sense of responsibility	Meeting other people in a similar situation	
The impact of young carers projects		Young carers services	
Calling young carers • Does the term young carer work? • Sense of responsibility		Young adult carers	
		Culturally specific	

Adapted stress process model for this sample of former young carers

The Stress Process Model for Young Carers						
Contextual Factors	**Primary Stressors**	**Secondary Stressors**	**Mediators**	**Outcomes**	**The Stress Process Model in a Young Carer Context**	**Using the Stress Process Model to Identify Support Needs of Young Carers**
Age-related factors	Unpredictability and threat arising from the illness	Lack of choice	Coping strategies and resources	Stressful/ negative outcomes	What is the difference between supported and unsupported young carers in their outcomes?	Informational support
Family structure	Prognosis of the illness	The nature of the caregiving role in mental health	Social support	Blame and guilt	Comparing young carers with and without support from young carer projects	Instrumental support
Cultural background	Being 'sectioned'	Lack of recognition for the young carer's expertise and inclusion in treatment	Barriers to getting help from services	Bullied at school	Mapping the model reflexively to the researcher's own experience	Emotional support
Relationship to the person with a mental illness	Loss of relationship with the ill person	Stigma and discrimination		Impact on work and education		Sources of support
		Financial difficulties		Emotional impact and impact on physical and mental health		Additional factors to be considered
				Positive impact of caregiving		Barriers and facilitators to providing help through services
						Who needs support?


CONTEXTUAL FACTORS
Young carers
Family structure
Cultural background
Relationship to PMI
MEDIATING FACTORS
Coping strategies and resources
Social support (instrumental/ emotional/informational)
- Family support
- Support from health services
- Support from young carers projects
Barriers to getting help
PRIMARY STRESSORS
Unpredictability and threat from illness
Prognosis of the illness
Being 'sectioned'
Loss of the relationship with the ill person
SECONDARY STRESSORS
Choice
The nature of the caregiving role
Lack of recognition of the young carer's expertise
Stigma and discrimination
Economic difficulties
Learning --> Adaptation
OUTCOMES
Stressful/negative descriptive outcomes
Blame and guilt
Bullied at school
Isolation
Impact on work and education
Emotional impact
Impact on physical and mental health
Positive outcomes

Appendix 3.1: Sample strategy, sibling search

1. (sibling* or brother* or sister*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
2. exp mental health/
3. mental illness*.mp.
4. exp mental disease/ or mental disease*.mp.
5. mental disorder*.mp.
6. exp depression/ or depression.mp. or exp bipolar depression/ or exp major depression/
7. depressive disorder.mp.
8. affective disorder.mp. or exp mood disorder/
9. bipolar.mp.
10. psychosis.mp. or exp psychosis/
11. psychotic.mp.
12. exp schizophrenia/ or schizophreni*.mp.
13. exp bipolar disorder/ or exp bipolar II disorder/ or bipolar.mp. or exp bipolar I disorder/
14. 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15. 1 and 14
16. intervention*.mp. or exp intervention study/
17. intervention studies.mp.
18. RCT.mp.
19. randomized controlled trial/
20. exp community trial/ or exp "randomized controlled trial (topic)"/
21. "complex intervention".mp.
22. 16 or 17 or 18 or 19 or 20 or 21
23. 15 and 22
24. **limit 23 to (human and english language)**

Appendix 3.2: Sample strategy, young carers search

1. (young informal carer* or young informal caregiver*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
2. (young carer* or young caregiver*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
3. (child carer* or child caregiver*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
4. (adolescent carer* or adolescent caregiver*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
5. (informal carer* or informal caregiver*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
6. exp Mental Health/
7. exp Mental Disorders/
8. (mental disease* or mental illness*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
9. exp Schizophrenia/
10. exp Psychotic Disorders/
11. exp Bipolar Disorder/
12. exp Depression/
13. 6 or 7 or 8 or 9 or 10 or 11 or 12
14. 1 or 2 or 3 or 4 or 5
15. 13 and 14
16. limit 15 to (english language and humans and yr="1985 - 2010")
17. intervention*.mp. or exp Intervention Studies/
18. **16 and 17**

Appendix 3.3: Number of references found from each search and database								
	SCIE SEARCH UPDATE		USING YOUNG CARER TERMS		USING SIBLING TERMS		FINAL UPDATE	
DATABASE	No. of refs found	No. of refs screened (after removal of 1701 duplicate refs)	No. of refs found	No. of refs screened (after removal of 173 duplicate refs)	No. of refs found	No. of refs screened (after removal of 300 duplicate refs)	No. of refs found	No. of refs screened (after removal of 348 duplicate refs)
Embase	623	446	81	54	406	366	350	308
Medline	179	1563	96	35	125	38	391	319
PsycInfo	826	549	77	44	196	145	143	112
CINAHL (Cumulative Index to Nursing and Allied Health Literature)	190	1294	59	28	96	40	490	436
Cochrane Library	124	1095	18	18	92	78	569	505
HMIC (Health Management Information Consortium)	70	27	7	2	9	3	54	28
ASSIA (Applied Social Sciences Index and Abstracts)	113	46	2	1	9	4	50	27
Campbell Collaboration	79	69	5	4	14	13	30	30
ERIC (Education Resources Information Centre)	41	14	14	12	58	41	26	13
National Criminal Justice Reference Service Abstracts	49	31	1	1	34	30	9	6
Social Services Abstracts	483	385	0	0	263	250	182	162
National Research Register Archive	N.A.	N.A.	0	0	533*	533*	N.A.	N.A.
Social Care Online	N.A.	N.A.	27	15	9	3	N.A.	N.A.
TOTAL	722	5519	387	214	184	1544	229	1946

*National Research Register Archive search results could not be exported and were screened online

Appendix 4.1. Presentation to nominal group

The BRC Young Carers Project

Nominal Group discussion
28/07/2011

1. Dealing with the illness

- ☐ knowing who to call in a crisis/emergency
- ☐ 24 hour no
- ☐ able to give advice and information
- ☐ kit/guide/action plan on discharge on what to expect, their findings, what to do, what not to do, steps to follow, including what to do for people who have occasional episodes (even a leaflet) (crisis card/plan?)

2. Contact for family in services

- professional in MH services who cares for carer
- someone sitting down and explaining the illness, what's going on, providing practical information, coping strategies - how to make sure you are looking after yourself
- actively engaging with family
- equipping carers for emergency/crisis, making sure they know who to call, how to respond
- group sessions for family with psychiatrist
- phoning to check up on them

3. Information

- information about illness needs to be tailored to be helpful
- knowing/understanding the terms to describe the patient's behaviour to professionals
- information about the different kinds of services available and how they can help, trying to understand the system
- understanding what hospitalization can achieve and talking over concerns

4. Respite

- time out
- activities
- respite house where both carer and person cared for can stay for a short break (or something along the lines of the Alzheimer's cafes? or a crisis house?)
- including person cared for
- somebody coming in, even for an hour

5. Schools

- activities organised through school for children whose parents would be reluctant to let them go out
- someone to talk to in school who knew what was going on, so it's not additional effort to go elsewhere
- awareness in schools - designated teacher, young carer groups, more support and understanding, young carer cards
- being identified earlier - with more awareness, teachers could spot the signs
- training teachers to be aware of the fact that kids can have responsibilities at home that can affect their performance and lives
- to what extent do children want their teachers involved, or want others to know about their lives at home?

6. Somebody to talk to

- somebody outside who will have a different approach
- knowing that people care - somebody phoning to check up on them
- counselling
- an adult that's not involved
- preferably someone who isn't a teacher in school, in case it becomes difficult
- somebody to contact for advice and support, for help with big decisions, for getting access to information

7. Meeting other people in a similar situation

- groups of patients and carers going out together, but depends on patients' circumstances and current state
- helps to know that other people are in a similar situation
- support groups
- shared experiences - providing activities during which people can open up
- similar age - yes or no?

8. Young carers services

- break
- meet other young carers
- someone who could come and explain things to school
- reassessment in case needs change
- somebody to talk to

9. Culturally specific

- culturally specific understanding and awareness of mental illness
- both community wide and individually
- information about the illness, helping with recovery, how to live with it
- from someone who understands the culture, its myths and barriers and has experience of working with mental illness

10. Young Adult Carers

- support, helping with future plans
- helping them feel like they can
- tailored service providing guidance and sign-posting rather than respite

All together

- Dealing with the illness (especially in an emergency/crisis situation)
- Contact for family in services
- Information
- Respite
- Schools
- Somebody to talk to
- Meeting other people in a similar situation
- Young Carers services
- Culturally specific
- Young Adult Carers

In addition

- needs to be a tailored approach
- need intervention for carers to combat stress and depression because if they're not well themselves, they can't look after someone else
- remembering that patient improvement always helps
- something outside the circle (NB help for people with social difficulties)
- it helps to have support from family (having other family carers for e.g.) and friends
- L.A. duty to provide for all YCs - should provide in different ways and be more proactive - not just one oversubscribed group
- need both knowledge and experience
- workshops in work places on carer and diversity awareness
- help with finances
- different people see different things as being what they need

Appendix 4.2. Topic guide for support worker interviews

Describe the mental illnesses on which the study focusses. Explain that the interview/ focus group will concentrate on young carers looking after somebody with these illnesses, unless specified otherwise.
Get them to describe their roles, how long they have been working with young carers, whether they have worked with young carers looking after someone with a mental illness.

TOPIC	PROBES
Work with young carers: in general, with young carers of mental illnesses, difference, examples	Can you tell me about your work with young carers? Can you tell me about your work with young carers who look after somebody with a mental illness, for e.g. schizophrenia or severe depression? Do you think there is a difference between the two groups? Could you give me case examples (without mentioning names of course)? What are the limits to your role?
Support for young carers: currently available, gaps	What are your opinions on the support that is available for young carers currently? Funding? What do you think the gaps are? / What gaps have you found in the support of young carers?
Interventions	In your experience, what do you think young carers caring for people with mental illnesses find most helpful? Can you give me examples of things that have helped them? What else might they find helpful that is not already available?
From our research: information, meeting other young carers, somebody to talk to	These were some of the things our participants felt were important: from your experience, do you think they would be helpful? Have you been unable to provide any of these? Could you tell me why? Have you provided any of these? Do you feel they were helpful for young carers looking after someone with a mental illness? If you have provided any of these, is there an element that you found most helpful? For e.g., if you have acted as the person that a young carer could talk to, what do you think they found most helpful about you providing that support? Can you foresee any difficulties? Or know from experience of difficulties that might be encountered? Would it be possible to support a young carer through sectioning and hospital as part of your role?

Appendix 4.3. Summary of themes from support worker interviews

Theme	Description
Support provided by young carer support workers and young carer projects	Young carers projects and their workers provided a range of interventions for young carers of people with both physical and mental illnesses
Difference between caring for somebody with a mental illness and a physical illness	Support workers were asked about the difference between young carers in their projects who were looking after people with physical and mental illnesses
Defining young carers	Support workers were asked whether they felt there was a difference between children living with and caring for somebody with a mental illness. A different approach was to examine the criteria employed by young carer projects in taking on children.
Barriers to supporting young carers	
Facilitators of support to young carers	
The response to suggested interventions	Support workers' responses to interventions suggested by participants varied from those who felt there was nothing new to those who felt there was a lot to think about
Building on existing work	While many of the suggested interventions seemed to be provided by the two young carers projects involved, there are still gaps